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Study of needs and service use among young people with attention deficit hyperactivity disorder at transition from adolescence to young adulthood

Eklund, Hanna

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**STUDY OF NEEDS AND SERVICE USE AMONG YOUNG PEOPLE
WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER AT
TRANSITION FROM ADOLESCENCE TO YOUNG ADULTHOOD**

Hanna Eklund

King's College London

Thesis submitted for the degree of PhD

2013

Acknowledgements

I would like to give a special thank you to my two supervisors, Dr Karen Glaser and Dr Kiriakos Xenitidis, for their support throughout this PhD. Karen Glaser, who is a Reader in Gerontology, has been unstinting in her support and enthusiasm during the course of this studentship. She has tirelessly worked through drafts of writing and provided excellent and constructive feedback while ensuring that I get comprehensive research training. In addition to this, her very warm personality has made working with her a true pleasure. Dr Kiriakos Xenitidis is a wonderful consultant psychiatrist and researcher whom I had the pleasure of working with at the Adult ADHD clinic at the Maudsley Hospital before the beginning of this PhD. He has been of great support ever since this time, and has never ceased to greet me with the biggest smile and a very generous spirit. Thank you both for your support.

I am also hugely grateful to all my colleagues whom I have worked with these past five years. I have been fortunate to work with researchers and clinicians from many different backgrounds, and this has enabled me to view the content of my PhD from several perspectives. Thank you to all members on the IMAGE project, especially Professor Philip Asherson, and to everyone on the wider NIHR programme, particularly, Professor Declan Murphy and Professor Jennifer Beecham and to all my colleagues at the Institute of Gerontology. To the National Institute for Health Research who funded this studentship, thank you for giving me the opportunity to carry out this research.

I would also like to extend my sincere thanks to all the families who participated in this research. They have kindly given up their time to take part in this research and also generously welcomed me to their homes, often spoiling me with extra comforts such as tea and biscuits or lifts to stations. Their kindness and very personal stories have moved me and made all the long hours of travelling required for this study very much worthwhile- thank you very much.

Lastly, I would like to thank my husband Nick and my son Ben for their support and for helping me to laugh and relax when this was needed the most.

Abstract

Background

Although there is increasing evidence that Attention Deficit Hyperactivity Disorder (ADHD) frequently persists into adulthood and is associated with high levels of impairments and comorbid disorders, few studies have examined needs, health service use and healthcare transitions among adolescents and young adults with ADHD. There are currently limited adult services for those with ADHD and little is known about their needs and the correlates of health service use in this group once they leave child and adolescent health services. Moreover, little is known about how the needs of this group are currently being met by family and friends and formal services.

Aims

To investigate needs and other associates of health service use among those diagnosed with ADHD in childhood who are now at transition from adolescence to young adulthood and their experiences of healthcare transition (i.e. the process of moving from child to adult health services).

Methods

82 participants were drawn from a clinical sample (the IMAGE project, an international collaborative genetic study of ADHD) consisting of 154 participants aged 14-21 years with a childhood clinical diagnosis of combined type ADHD. Face-to-face interviews and questionnaires were used to assess needs, as well as demographic and health factors associated with health service use and experiences of healthcare transitions between April 2009 and February 2011.

Results

Although ADHD symptoms had diminished since participants were children, 73% still experienced ADHD symptoms severe enough to warrant diagnosis. Moreover, levels of impairments and psychiatric comorbidities were high with 90% of participants reporting significant impairments in at least one daily activity and 27% meeting cut off for a neurotic

disorder. A wide range of needs were also reported, for example in money management, safety to self, inappropriate behaviour and self-care. Most help in meeting needs was from family or friends rather than from formal services.

Service use was not associated with ADHD symptoms or other need and enabling factors but was related to age, with younger participants being more likely to be in contact with services. Only eight participants had experienced a transfer from child to adult services (10%) including one who had received a written transition plan during the transition process. In addition, both young people and parents reported difficulties in the process of moving from child to adult health services, for example, gaps in provision of information about adult services and the transition process and lack of co-ordination of transition.

Discussion

This study adds to the (currently scarce) evidence base about health service use and needs of adolescents and young adults with ADHD and will further the debate within public policy as to how services should be designed and implemented for this group. The importance of addressing the wide range of needs of this group is highlighted as is the discrepancy between help provided by families and services in meeting the needs of this group. The role of age in determining service use and the need for more support from services in regards to the transition from child to adult health services is also emphasised.

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CHAPTER 1

Introduction

This introductory chapter sets out the aims and objectives of this study and outlines how these were approached. Following this, a brief background and rationale for undertaking this study is given, including an explanation of my personal motivation for carrying out this research and then a description of the larger study, of which this PhD formed part. An overview of the theoretical framework that was employed in this study is then set out as well as an outline of the structure of this thesis.

1.1 Aims and objectives

The main aim of this study was to investigate needs and service use among young people diagnosed with ADHD in childhood at transition from adolescence to young adulthood (aged 14 to 21 years). It specifically sought to identify the needs of this group and to establish the amount and type of help provided by services and families towards meeting these needs. Following Andersen's model of health service utilisation, consideration was also given to the predisposing, enabling and need factors associated with health service use (and mental health service use in particular) among this clinical group. In addition, this study sought to explore the experience of healthcare transitions, defined here as the process of moving from child to adult health services, among those with ADHD now aged 14 to 21 years.

The research objectives that this study sought to meet were:

- (i) To investigate the met and unmet needs among those with a childhood diagnosis of ADHD at transition from adolescence to young adulthood (aged 14 to 21 years) and the extent to which services and family members/friends are meeting the needs of this group;
- (ii) To examine the predisposing, enabling and need factors that are associated with health service use (and mental health service use in particular) among adolescents and young

adults at transition from adolescence to young adulthood (aged 14 to 21 years) who received a diagnosis of ADHD in childhood;

- (iii) To explore the experience of healthcare transition (transfer and process) among young people with a childhood diagnosis of ADHD during the transitional years from adolescence to young adulthood.

To meet these research objectives, two definitions of “service use” were adopted. In addressing research objective (i), the term “services” was used to denote all services in line with the use of the term in the Camberwell Assessment of Needs for Adults with Developmental and Intellectual Disabilities (CANDID), a needs assessment tool employed in this study. Using this broad definition of “services” meant that information could be collected on all help received from any services towards meeting the needs of this group in addition to all help received from informal sources such as family and friends. To achieve research objectives (ii) and (iii), however, the term “services” was used to refer to health services only in line with Andersen’s model of healthcare service utilisation (Andersen, 1968, Andersen, 1995), the theoretical model applied to examine correlates of service use in this study. A focus on health services only, mental health services in particular, also allowed for a more focused examination of transition within one service setting only.

Similarly, this thesis defined “transition” in two ways. To achieve research objectives (i) and (ii) “transition” was used solely to refer to “the transitional years from adolescence to young adulthood (14 to 21)”. These years correspond to a critical period in the lifespan during which many important changes in social, sexual and identity development occur over time (Davis 2003, Eiser 1993). These are also years during which young people are particularly vulnerable to poor mental health despite recent improvements in living conditions and better physical health. In addition, adolescents and young adults are likely to fall between child and adult services and have a greater likelihood of disengagement from services when compared to other age groups (Lamb et al. 2008, Newman et al. 1996). Thus, “transition” was used to pertain to a critical period during which many changes are likely to take place. In contrast, in meeting research objective (iii), “transition” was used specifically to refer to healthcare transition, defined as the process of moving from child to adult health services. From this perspective, transition refers to both the act of *transfer* (e.g. moving) from child to adult health services, particularly mental health services, and the *process* involved in preparing the young person and family for transfer to adult care.

While research objective (iii) focuses on healthcare transition, it is recognised that healthcare transitions are only one of several transitions that young people with a childhood diagnosis of ADHD are likely to undergo between the ages 14 and 21. In addition to healthcare transitions, other transitions among this group may include moving from social care services for children to social care services for adults, moving away from home, leaving school to go to university and entering the workforce, to name only a few. It is hoped that by employing these definitions of “transition” and “services” to assess needs and service use, this study will help to inform how services and family members are currently meeting the needs of young people with a childhood diagnosis of ADHD as well as furthering public policy debate on how effective care programmes may be devised and implemented to better care for this group.

1.2 How these aims and objectives were investigated

To achieve the first research objective, the CANDID was chosen as the most appropriate measure to investigate needs in this group following piloting of this instrument at the Adult ADHD clinic at the Maudsley Hospital in London. This measure enabled the investigation not just of needs associated with ADHD but of a comprehensive range of universal needs. Moreover, it also allowed for the examination of the type and amount of help provided by family and friends (informal help) and services (formal help) in meeting the needs of this group. Descriptive analyses enabled the current type and amount of help provided by informal and formal sources to be measured and analysed.

To investigate the second research objective, predisposing, enabling and need variables of both the young person and parent were investigated through a series of structured and semi-structured face-to-face interviews as well as self-completion questionnaires. A sample of young people with a childhood diagnosis of ADHD and their parents were interviewed during home visits over a period of 21 months in 2009 to 2011. An adapted version of the Client Services Receipt Inventory, which included a series of demographic, service use, and healthcare transition questions, was designed for this study while a range of clinical measures were used to investigate need variables such as ADHD symptoms, psychological symptoms, alcohol and drug use and problems with police using structured and semi-structured interviews and self-completion questionnaires. These included the Diagnostic Interview for Adults with ADHD (DIVA), the Clinical Interview Schedule - Revised (CIS-R), an

abbreviated version of the Alcohol Use Disorders Identification Test (AUDIT-C), as well as a series of questions concerning drug use and problems with police through the use of self-completion questionnaires. Together, these measures enabled bivariate and multivariate analyses, including logistic regression, to be conducted to explore predisposing, enabling and need factors associated with health service use. To explore healthcare transition among this group (i.e. the third research question), a series of questions on healthcare transition were asked as part of the adapted version of the CSRI. These included questions regarding the nature and timing of transition planning, information sharing, co-ordination of transition, and attending to the needs of young people and parents which enabled the experiences of healthcare transition among this group to be explored descriptively.

1.3 Background to this study

The topics covered in this thesis have been of personal interest to me since I began working as an assistant clinical psychologist at the Adult ADHD clinic at the Maudsley Hospital. During my time there, I saw first-hand how many people with ADHD struggle with day-to-day activities and suffer from low self-esteem. It appeared to me that there was a demand for services to assess and treat adults with ADHD, yet not many services existed for this clinical group. I learned that few studies had examined service use and needs among this group (and in particular among those with a childhood diagnosis of ADHD who were now in late adolescence or young adulthood) and this prompted me to do some research in this field.

This study formed part of a wider 5 year programme (funded by the National Institute for Health Research (NIHR)) entitled “Crossing the divide: Effective treatments for people with neurodevelopmental disorders across the lifespan and intellectual ability”. Within this programme the study was part of a three-year longitudinal study examining needs and service use among young people diagnosed with ADHD or Autistic Spectrum Disorders (ASD) in childhood who were now at transition from adolescence to young adulthood. I was responsible for the day-to-day management of this latter study. It was necessary to employ a research assistant to help with data collection from parents in order to enable two parallel interviews to be conducted with the young person and the parent. Save for this data collection of parent data, the work undertaken for this PhD (which is based on the baseline data), including the collection of all the young person and joint (parent and young person) interview data, is my own.

A study aimed at informing the creation of more effective services and treatments for adolescents and young adults diagnosed with ADHD is critical considering that the prevalence of ADHD is much higher than previously thought, affecting some 4% of children, of whom about two thirds have functional impairments in adult life (Faraone et al. 2006, Ford et al. 2003). ADHD disrupts normal academic and social development and is associated with learning disabilities, and behavioural/psychiatric disorders, such as antisocial behaviour, drug abuse, anxiety and depression (Barkley et al. 2006, Weiss and Hechtman 1993). ADHD is therefore a significant problem in young adults (Asherson 2005) and implies high use of health and social services and negative impacts on family and personal life.

Improving mental health for people of all ages is a key concern in policy initiatives such as “No health without mental health: a cross-government mental health outcomes strategy for people of all ages” (Department of Health 2011a). For young people with mental health problems, the National Services Framework (NSF) for mental health highlighted the importance of providing adequate services, including (standards 1-3 and 6) the need to increase inclusion, and to deliver services that meet the needs of both users and their carers (Department of Health 2004). Moreover, determining how needs are affected by comorbid disorders is a critical policy issue because care needs and costs are greatest among the most disabled (McCrone et al. 2008). Recent estimates suggest that the total annual cost of health services utilised by young people suffering from the most frequently occurring disorders (depression, conduct disorder (CD) and ADHD) is approximately £143 million, and is projected to increase to £237 million by 2026 (McCrone et al. 2008). However, these figures represent only a proportion of the total burden, which falls not only on specialist Child and Adolescent Mental Health Services (CAMHS) but also on the young people and their families, on the wider health service and various other service providers, including Local Authority Personal Social Service and Education Departments, voluntary and private sector providers and the youth and criminal justice sectors (Barrett et al. 2006, Bebbington and Beecham 2007, Ginsberg and Lindefors 2012, Romeo et al. 2006, Young et al. 2011a).

While many studies have investigated needs and service use of children with ADHD (Bussing et al. 2003c, Sayal et al. 2006, Sayal 2010) to date little is known about the needs and service use of young people with a childhood diagnosis of ADHD at transition to adolescence and young adulthood. ADHD has until recently been regarded as a childhood disorder despite increasing evidence showing its persistence into adulthood. Consequently,

few studies into service use and needs of adolescents and young adults with ADHD have been conducted (Bussing et al. 2011, McCarthy et al. 2009, Taylor et al. 2010, Wong et al. 2009). Nevertheless, growing evidence suggests that many more young people with developmental disorders continue to experience functional impairments and symptoms into adulthood and therefore have urgent needs that are currently being unmet by services. Lack of services for those leaving CAMHS with ongoing needs and functional impairments mean that family members are likely to have become integral to the care of these patient groups. Hence, research into the needs and service use of young adults with ADHD and their carers is important in order to (i) better design and implement appropriate and effective care programmes and (ii) provide support for carers of adolescents and young adults with this disorder.

Although studies have identified substantial support needs for those with ADHD in terms of medical, social and educational services, to date little is known about (i) use of specialist services, and (ii) use and duration of medication and other treatments among adolescents and young adults with ADHD. Most studies investigating specialist service use among those with ADHD have focused on children. Even among this age group studies have suggested there is significant under-treatment and unmet need. For example, Sayal and colleagues (2006) using nationally representative data from the 1999 British Child and Adolescent Mental Health Survey found that only one third of children, (aged 5 to 15 years), with ADHD had received specialist services and hence were in a position to access evidence based treatment (Sayal et al. 2006).

Continued access to services in adulthood is crucial given that considerable research has shown that ADHD often persists into adulthood and frequently with continued negative impacts. Moreover, recent government papers (Department of Health 2008, Kennedy 2010) stress the importance of the provision of continuity in transition from child to adult health services. Healthcare transition is an important dimension of high quality service provision. Failure to provide good transition for young people with complex and ongoing needs means that any gains made by children's services may be undermined or lost and more importantly, that young people and carers are likely to experience unnecessary distress. Yet, currently few studies have looked into healthcare transition in adolescents and young adults with ADHD. Consistent problems affecting the failure to provide effective transitioning have been identified which include (i) inconsistency of referral and treatment criteria, (ii) poor

communication between services, (iii) lack of continuity, (iv) conflict between the child/family approaches of paediatric and the individual approach of adult mental health services, and (v) the disengagement of young adults who drop out of the healthcare system (Health Select Committee 2000). Significant problems remain in provision of services for 16 to 17 year olds and hence research into the needs and service use among people with ADHD who often have ongoing and complex needs is important.

This study will be significant in adding to the (currently scarce) evidence base about needs and health service use among this clinical group by providing knowledge about (i) met and unmet needs; (ii) the role of family members and services in meeting the needs of this group; (iii) enabling, predisposing and need factors associated with health service use; and (iv) healthcare transition (transfer and processes) among young people with a childhood diagnosis of ADHD during the transitional years from adolescence to young adulthood.

1.4 Theoretical and conceptual framework

The health services model proposed by Andersen and colleagues (Andersen 1968, Andersen 1995, Andersen and Newman 1973) serves as the fundamental theoretical framework for this study. It is an established framework widely used by health economists, psychologists, and medical sociologists to explain patterns of health service use among diverse populations (Fosu 1994, Smith and Kirking 1999). The model organises health service use into predisposing, enabling and need categories whereby health service use is conceptualised as a function of predisposing variables (such as the person's age and gender or living arrangements), by enabling factors (such as knowledge of health services that may enable or impede service use) and need factors (such as medical status and perceived burden). The literature on service use suggests that need variables explain more variations than predisposing or enabling variables (Wolinsky 1990) however, it is unclear how these may be related to health service use during the transition from child and adolescent to adult services.

This study will consider both the individual characteristics of the young person and the caregiver in influencing the care recipient's use of health services, and mental health services in particular (See for example, Bass and Noelker 1987). Caregivers can influence health service use both directly (by contacting agencies on behalf of the care recipient) and indirectly (by influencing the care recipient's perceptions). For many young adults with

developmental disabilities, particularly those with low intelligence, caregivers are likely to be important decision-makers, with respect to seeking, obtaining and continuing use of health services. Hence, emphasis has recently been given to developing policies to provide support for family carers of relatives (National Institute for Clinical Excellence 2008, Young et al. 2011b). Measures of socio-economic status, such as education, may be important as they may hinder or enable health service use in this group.

1.5 Structure of thesis

This thesis consists of 9 chapters. Chapter 2 provides a background of ADHD, giving a brief summary of the history of the concept and how it has evolved over the decades, highlighting some of the current controversies and myths that still exist around the disorder. A brief summary of the epidemiology of this disorder is given as well as a description of how symptoms and associated comorbidities may be linked to the course of the disorder and persist into adulthood. This chapter reviews which factors are associated with ADHD and which factors have been shown to persist into adulthood or emerge due to difficulties in coping with the core ADHD symptoms in childhood.

Chapter 3 focuses on current guidelines with regard to the diagnosis and management of ADHD and reviews the literature on how these are being met in practice. Current failings to provide services and support for adolescents and young adults with ADHD in line with the recommendations of these policy guidelines are reviewed.

Chapter 4 presents the conceptual framework of this research and provides a review of the literature on factors associated with health service use among young people (e.g. adolescents and young adults) with mental health problems and those with ADHD specifically. The key dependent variables are defined and conceptualised and the principles that underpin the measures used in this research are presented. A justification for choosing Andersen's behavioural model of health service use is given. Last, the predisposing, enabling and need variables chosen in this research are discussed.

In Chapter 5, an outline of the methods used in this research is given. The instruments developed for this study are described and a rationale for choosing the other measures is provided. The process of data collection and data analysis is also explained.

Chapters 6, 7, and 8 present the results of this research. Chapter 6 gives a general background of the sample and explores how many of the participants had retained an ADHD diagnosis in late adolescence/early adulthood. This chapter also presents findings regarding the sample's comorbidities and level of impairment, and investigates whether or not these were associated with ADHD. Chapter 7 then focuses on the met and unmet needs of the sample and to what extent needs were met by help provided by families, friends and services (addressing research objective (i)). It also examines which factors were associated with needs (e.g. ADHD, comorbidities or impairments, reviewed in Chapter 6). The last results chapter, Chapter 8, focuses on health service use among those with a childhood diagnosis of ADHD at transition from adolescence to young adulthood and explores what predisposing, enabling and need factors are associated with health service use in this group. It then goes on to explore the healthcare transition among this group. This includes transfer from child to adult health services as well as processes aimed at preparing the young person and family for the transfer (addressing research objectives (ii) and (iii)).

Finally, Chapter 9 brings together the results of the face-to-face interviews and self-completion questionnaires and provides a discussion of these in the context of literature discussed in Chapter 3 and the conceptual framework discussed in Chapter 4. Findings are compared to previous studies and the strengths and limitations of this work are discussed. The implications of this study are described and recommendations for areas of further research and policy and practice are drawn out.

CHAPTER 2

Background

2.1 Introduction

This chapter gives a general overview of ADHD, beginning with a brief history of how the concept of ADHD has evolved over the years before outlining the epidemiology of this disorder. It shows that ADHD is still an under-recognised, under-treated and controversial disorder, which is associated with burdens and costs not only for the individuals and families of those affected, but for the whole of society.

2.1.1 A brief history

Attention Deficit Hyperactivity Disorder (ADHD) as a concept has a long and varied history that has seen many definitions and ideas over the last hundred years. In the early 1900s the British paediatrician George Still was one of the first to pay serious medical attention to the behavioural condition in children that today most closely approximates what is known as ADHD. In his series of lectures to the Royal College of Physicians (Still 1902), he described 20 children in his clinical practice who were often “aggressive”, “defiant”, and “resistant to discipline”; were excessively emotional or “passionate” (p 1009); and showed little “inhibitory volition” (p. 1008). “Lawlessness” (p.1009), spitefulness and cruelty, and dishonesty were also associated with this disorder. Most of these children were impaired in attention and were quite overactive.

Still believed that these children displayed a major “defect in moral control” (p.1009) in their behaviour, and that this was relatively chronic in most cases. In some cases, it was acquired secondary to an acute brain disease and was thought to remit upon recovery from the disease. Today, some leading authors in the field of ADHD have noted that many of the children whom Still described would probably now be diagnosed as having not only ADHD but also Oppositional Defiant Disorder (ODD) or Conduct Disorder (CD) and most likely some sort of Learning Disability as well (Barkley 2009). Nevertheless, fundamental to this and other

published conceptualisations of the disorder at the time was the idea that these were disturbances of behaviour caused by brain damage or “minimal brain dysfunction” (MBD), such as were seen in the pandemic of encephalitis in the 1920s or after a traumatic birth (Barkley 2009).

A change in the conceptualisation and definition of ADHD occurred in the 1980s when the American Psychiatric Association began to classify mental health disorders according to its diagnostic scheme DSM-III (later DSM-IV) similar to the World Health Organization’s classification of diseases ICD-9 (now ICD-10) (American Psychiatric Association 2000). These classification schemes were again, like the earlier brain damage theories of ADHD based on observations about how people behave: showing maladaptively high levels of impulsivity, hyperactivity and inattention where “impulsivity” signifies premature and thoughtless actions; “hyperactivity” a restlessness and shifting excess of movement; and “inattention” a disorganised style preventing sustained effort.

Since this time, clinical and statistical studies have indicated that impulsivity, hyperactivity and inattention were often associated and were found to be disproportionately common in children referred for psychiatric help. Thereafter, in North America the term “attention deficit hyperactivity disorder” was applied to moderate to severe levels of the disorder whereas in most of Europe, only extreme levels were seen as an illness and called “hyperkinetic disorder”.

2.1.2 Current conceptualisations of ADHD

Today, further changes to the conceptualisations of ADHD have emerged as a result of extensive biological investigations of both ADHD and hyperkinetic disorder (Cantwell 1996, Faraone et al. 2000b, Morrison and Stewart 1971, Thapar et al. 1999). These have yielded some neuroimaging and molecular genetic associations and have resulted in neurocognitive theories of ADHD which are thought to present a better understanding of the natural history and the risks imposed by the disorder (National Institute for Clinical Excellence 2008). The terminology in the UK has also changed, and “ADHD” has become the diagnostic phrase most commonly used in practice (even when more restrictive criteria are being used) (National Institute for Clinical Excellence 2008).

ADHD is currently conceptualised as a heterogeneous disorder affecting both males and females which covers considerable variation in the degree of symptoms, pervasiveness of the symptoms across situations, and the extent to which other disorders occur in association with it (Barkley 1998, Barkley 2006, Wender 1995, Wilens et al. 2002). While some individuals have the combined-type version of ADHD (involving persistent and frequent levels of the core symptoms of hyperactivity, impulsivity and inattention), others have the predominantly hyperactive and impulsive type while still others are principally inattentive. ADHD often persists into adulthood and is associated with a range of impairments and adversities in adulthood.

2.1.3 A controversial disorder

Despite the increasing evidence from neuropsychological, genetic and neuroimaging studies that have indicated that ADHD is a real and complex neurobiological disorder (Faraone et al. 2000b, Asherson et al. 2005, National Institute for Clinical Excellence 2008, Thapar et al. 1999), ADHD remains a controversial disorder. Certain sections of the media continue to portray ADHD as a “sign of the times”, as a disorder which is not “real” but which is an American fad or the product of poor parenting/environment (Mayes et al. 2008). As such it is often presented as a disorder which conveys a constellation of behaviours that parents and schools have become unwilling or unable to tolerate (McLeod et al. 2007). According to these critics, parents and teachers accept diagnostic labels and psychostimulant medication prescription because they offer relatively straightforward, inexpensive, and fast-acting solutions to complex problems (Breggin 1998, DeGrandpre 1999, Diller 1998). By implication, they claim that ADHD is overdiagnosed and that children are receiving unnecessary and inappropriate treatment.

Similarly, there remains widespread controversy among clinicians regarding the validity of ADHD in adulthood which has only recently become the focus of widespread clinical attention (Wilens et al. 2004). Some primary care and mental health professionals continue to question the ethical and diagnostic validity of the disorder due to lack of agreement on appropriate diagnostic criteria and the realisation that diagnosis is complicated by symptom overlap with a number of other disorders (McGough and Barkley 2004). The controversy is particularly obvious in the criminal justice system over the question of an individual’s moral responsibility and how it is affected, if at all, by a condition such as ADHD. Other mental

health professionals state that although the distinction between ADHD and other disorders such as bipolar disorder, particularly bipolar 2, may be difficult (as symptoms of irritability, excessive activity, impulsive behaviour, poor judgement and denial of problems are characteristics of both disorders) (Nierenberg et al. 2005), ADHD can be distinguished by its persistent character in comparison to the episodic nature of bipolar disorder (Asherson et al. 2007).

On the one hand, scepticism among primary care and mental health professionals about the validity of the concept of ADHD in adulthood is likely to lead to less recognition and treatment despite the often devastating consequences of the disorder. On the other hand, the increasing media attention in ADHD means that patients and their families are becoming increasingly aware and informed about the condition and available treatments. As a result, demands on physicians with respect to existing treatments is likely to increase, which in turn may result in raised awareness and understanding of ADHD among health professionals.

The following section will give an outline of the epidemiology of ADHD, providing more detail of the current conceptualisations of ADHD particularly in adulthood.

2.1.4 Core symptoms and diagnosis

The diagnosis of ADHD is most commonly based on criteria set out in the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV) and the International Classification of Mental and Behavioural Disorders 10th revision (ICD-10). The DSM (which first introduced “ADHD” in the DSM-III-R in 1987) breaks down symptoms into two groups: inattentive and hyperactive/impulsive. Six of the nine symptoms in each category must be present for a “combined type” diagnosis of ADHD. In cases where there are insufficient symptoms for a combined diagnosis then predominantly inattentive (ADHD-I) and hyperactive (ADHD-H) diagnoses are available. The DSM sets out that for a diagnosis to be made symptoms must be (i) present by the age of seven; (ii) chronic (present for at least 6 months); (iii) maladaptive; (iv) functionally impairing across two or more contexts; (v) inconsistent with developmental level; and (vi) differentiated from other mental disorders (National Institute for Clinical Excellence 2008).

Although hyperactivity is important, according to the DSM it is not a benchmark of diagnosis per se and is viewed as less prevalent by the teenage years. It is also viewed as less common

among girls – who often have the predominantly inattentive type of ADHD but still experience significant problems because of their poor concentration. Moreover, ADHD symptoms are viewed as being present in most people at some time (like depression), but as occurring more persistently and frequently among those who meet diagnostic criteria, causing impairments across different contexts.

The same symptoms are used in the ICD (which first introduced ADHD in the ICD-8 in 1968) but with a different nomenclature. According to ICD-10, symptoms must be present by the age of six years and are described as part of a group of hyperkinetic disorders of childhood. Inattention, hyperactivity and impulsivity must all be present and therefore only “combined-type” ADHD qualifies. In addition, the symptom counts must all be met in more than one context whereas coexisting psychiatric disorders are allowed under DSM-IV. Moreover, the diagnosis of hyperkinetic disorder is not made when criteria for certain other disorders, including anxiety states, are met unless it is plain that hyperkinetic disorder is additional to the other disorder (National Institute for Clinical Excellence 2008). The ICD-10 classification therefore captures a more severe form of the disorder than DSM-IV.

In summary, two main diagnostic criteria for ADHD are in current use: the DSM-IV and the ICD-10. DSM-IV has a broader, more inclusive definition and includes a number of different ADHD subtypes whereas ICD-10 uses a narrower diagnostic category and includes people with more severe symptoms and impairment (National Institute for Clinical Excellence 2008). As this thesis was interested in capturing a broader definition of ADHD rather than just the severest type of ADHD that is encapsulated in the ‘Hyperkinetic disorder’ (ICD-10) definition, the DSM-IV definition of ADHD was used. This was felt to be important as symptoms of ADHD are likely to change as young people with ADHD transition into adolescence and adulthood with inattentive symptoms more likely to persist than hyperactive symptoms (National Institute for Clinical Excellence 2008).

Notably, the recognition and diagnosis of ADHD depends on how these symptoms are perceived by parents and other important adults who deal with or live with the hyperactive child (such as teachers) (Barkley 2003). Mild forms need not be impairing (Mannuzza et al. 1998); however, in most cultures extreme forms are considered to be harmful to the individual’s development. Cultural differences do exist with respect to the type and degree of behaviours that are regarded as a problem (Sonuga-Barke and Balding 1993). For example,

while both teachers and parents can find it hard to deal with or live with a hyperactive child, their tolerance and ability to cope may determine whether the hyperactivity is presented as a problem (Barkley 2003).

2.1.5 Aetiology

ADHD appears to involve the interplay of multiple genetic and environmental factors which together produce different combinations of risk factors. As such these factors are thought to underlie the varied behavioural problems contained in the heterogeneous disorder (National Institute for Clinical Excellence 2008). Twin studies indicate that around 75% of the variation in ADHD symptoms in the population are because of genetic factors (Faraone et al. 2005) and brain studies also suggest that certain regions of the brain are involved to produce ADHD symptoms, of which the prefrontal cortex and subcortical structures such as the basal ganglia appear to be most involved (Spencer et al. 2002). A range of environmental factors are also thought adversely to affect brain development during perinatal life and early childhood and increase the risk of ADHD (McArdle 2004). These include maternal smoking (Linnet et al. 2003), alcohol consumption (Mick et al. 2002), heroin during pregnancy (Ornoy et al. 2001), low birth weight (Botting et al. 1997), brain injury and exposure to toxins such as lead (Toren et al. 1996). Secondary ADHD may also follow traumatic brain injury (Gerring et al. 2000). ADHD has also been associated with severe early psychosocial adversity, for example, in children who have survived deprived institutional care (Roy et al. 2000).

2.1.6 Prevalence

Based on the narrower criteria of ICD-10, hyperkinetic disorder is estimated to occur in about 1–2% of children and young people in the UK. Using the broader criteria of DSM-IV, ADHD is thought to affect about 3–9% of school-age children and young people in the UK (National Institute for Clinical Excellence 2008). However, US studies have put the estimated prevalence of ADHD between 8-12 % (Biederman and Faraone 2005). Moreover, a prevalence study in Columbia, South America, found a prevalence rate of 20% and 12% (for boys and girls respectively) aged 4-17 years (Pineda et al. 2003). Variations in the prevalence of ADHD in the international literature are unlikely to reflect true differences in the percentage of individuals with ADHD but are more likely to reflect ethnic and cultural differences as well as differences in methodological features across studies, for example, in

the method of diagnostic systems and assessment (National Institute for Clinical Excellence 2008, Polanczyk et al. 2007).

In reviewing the worldwide prevalence of ADHD Polanczyk and colleagues (2007) concluded that most of the variability across studies derived from the methods used, for example, impairment criterion, diagnostic criteria and source of information (i.e. whether or not information provided by parents or teachers was used (Polanczyk et al. 2007). For example, applying the same methodological procedures and diagnostic criterion, very similar rates of ADHD/HD were found in Russia (Goodman et al. 2005) and Britain (Ford et al. 2003). However, when the diagnosis of ADHD/HD was made in the same geographic location but according to a different methodological criterion (i.e., with or without the requirement of functional impairment) estimates ranged from 4% to 9% (Canino et al. 2004).

However, even where the same diagnostic definitions are applied, there are likely to be differences in the thresholds applied for individual symptoms, which are rarely operationalised. For example, how severe should the avoidance of tasks requiring sustained attention or levels of fidgetiness be before they are considered clinically significant? Key criteria when defining ADHD include not only the presence of sufficient numbers of ADHD symptoms but also, importantly, their association with clinical and social impairments at home, school and in other settings. Surveys that include strict definitions of impairment alongside the symptom count find that prevalence of the syndrome (without evidence of impairment) is around twice the prevalence of the disorder when the syndrome is associated with impairment (Canino et al. 2004). In the UK, a survey in Newcastle found that prevalence was 11% for ADHD (the syndrome with no impairment), 7% when associated with moderately low impairment, 4% for moderate impairment and 1% for severe pervasive impairment (McArdle et al. 2004). Taking into account the differences in investigator training and measures used across studies it is not possible to draw firm conclusions from the large variation in prevalence rates cited in the literature.

Fewer studies have examined prevalence rates of ADHD among adolescents and young adults. Those studies that do exist show that adult prevalence rates for ADHD vary from 1% to 6% of the general population (Biederman and Faraone 2005, Kessler et al. 2006, National Institute for Clinical Excellence 2008, Wender 1995), with recent longitudinal studies in the US (following children with ADHD into adulthood) estimating it to be approximately 3% to

5%. For example, a study carried out in an adult general population sample by Kessler and colleagues in 2005 found an estimated prevalence of adult ADHD to be 4% (Kessler et al. 2005). However, a recent meta-analysis by Simon and colleagues (2009) estimated the worldwide prevalence of adult ADHD to be 3%. These authors found that the prevalence of ADHD among adults is lower than among children but noted that their estimate of 3% may be an underestimate due to questions over the validity of using DSM-IV diagnostic criteria for adult ADHD (Simon et al. 2009).

Studies indicate that by the age of 25 years half of people diagnosed with ADHD as children will show continued impairing symptoms that are consistent with the DSM-IV diagnosis in partial remission, and about 15% will have retained full diagnosis (Faraone et al. 2006). Yet, despite the partial remission of symptoms in adulthood, prospective follow-up studies show that when children with ADHD reach adolescence and adulthood, they remain at risk for ADHD related impairments (Fischer et al. 2002, Rasmussen and Gillberg 2000).

Adult outcome studies of large samples of clinic-referred children with hyperactivity, or ADHD-combined type, are few in number (Barkley 2009). Only five follow-up studies, to the author's knowledge, have retained at least 50% or more of their original sample into adulthood (Barkley et al. 2002, Ford et al. 2008, Mannuzza et al. 1993, Rasmussen and Gillberg 2000, Weiss and Hechtman 1993). These studies show that at least 50% of children with ADHD continue to suffer from the condition or some symptoms of it in young adulthood. For example, Weiss and Hechtman (1993), who carried out a longitudinal study in Canada (N=103), found that two thirds of their original sample (n=64; mean age of 25 years) claimed to be troubled as adults by at least one or more disabling core symptoms of their original disorder (restlessness, impulsivity or inattention) and that 34% had at least moderate to severe hyperactive, impulsive, and inattentive symptoms (Weiss and Hechtman 1993, p. 73). In Sweden (n=50), Rasmussen and Gillberg (2000) obtained similar results, with 49% of probands reporting marked symptoms of ADHD at age 22, compared to 9% of controls (Rasmussen and Gillberg 2000).

More recently Ford and colleagues (2008) followed up a clinical sample of 115 adolescents and young adults in the UK who were initially assessed and diagnosed with ADHD (according to DSM-IV) or hyperkinetic disorder (ICD-10) five years earlier at the ages of 6-15 years (mean age 9.4 years, sd. = 1.7). At follow-up, 80% of the child sample was retained

and completed the same diagnostic instruments as at baseline. This study found that most adolescents (70%) continued to meet full DSM-IV criteria for ADHD when assessed using the parent version of the Child and Adolescent Psychiatric Assessment (CAPA) and the Child ADHD Teacher Telephone Interview (ChATTI) to measure symptoms and impairment at school (Langley et al. 2010). The study also examined a range of key adolescent outcomes considering whether maternal and social factors influence the course of ADHD (to be described in section 2.2.10).

Among adolescents and young adults, self-report of symptoms yields lower persistence rates than parental reports. For example, using self-report of DSM symptoms, Barkley and colleagues (2002) noted that persistence in a group of 19 to 25 year olds could be seen in as little as 5%, whereas in the same study, the value rose to 46% when parental report was used (Barkley et al. 2002). Moreover, in a more recent review, Barkley (2008) noted that when parent reports of the subjects are used persistence of disorder was 14 times higher (Barkley 2008). Young people with ADHD may therefore be seriously prone to underreporting their symptoms relative to what others say about them.

However, there is some evidence to suggest that, with increasing age, young people with ADHD show an increase in the self-report of symptoms. Barkley (2009) noted that whereas informant reports normally show declines in symptoms and disorder, self-reports tend to show an increase in both at follow-up at ages 21 and 27 (Barkley 2009). Barkley hypothesised that this may be largely because most childhood cases report themselves as having no disorder at age 21, but then begin to realize in the interim that they most likely do have ADHD symptoms. Given this increasing insight into their ADHD symptoms, their reports begin to converge with informant reports at older ages (Barkley 2009).

Estimating the prevalence of adult ADHD is further complicated by the fact that using full DSM criteria for defining ADHD in adults may be inappropriate, given that it was designed for children (Barkley 2009). It has been argued that the manifestation of the disorder changes as the individual ages (Davidson 2008), and that use of criteria developed for use in children is not developmentally sensitive and therefore not appropriate for use in adults (Riccio et al. 2005).

However, despite these current difficulties of establishing the prevalence of adult ADHD, the current consensus is that ADHD continues to be a problem in adulthood for a significant proportion of individuals who have grown up with the disorder.

2.1.7 Course of the disorder and persistence into adulthood

The core behaviours of ADHD are typically present from before the age of 7 years and lead to developmental impairments among children. Several studies have followed diagnosed school children over periods of 4 to 14 years. All have found that these children tend to show, by comparison with other people of the same age who do not have mental health problems, persistence of hyperactivity and inattention, poor school achievement and a higher rate of disruptive behaviour disorders (Faraone et al. 2006).

For several decades it was thought that ADHD was restricted to childhood and the idea that ADHD persisted into adulthood was met with considerable scepticism. It was widely believed that once an individual reached adolescence or early adulthood they would outgrow the hyperactive, impulsive and inattentive behaviours. For example, following a discussion of the clinical features of what would now be called ADHD, Laufer (1962) noted:

“The behavioural picture (of ADHD) tends to disappear with maturation, anywhere between the twelve and eighteen years of age, so that it may no longer be present, though its unfortunate educational and emotional sequel may persist” (Laufer 1962, p. 504).

Similarly, in the context of a follow-up study, Mendelsohn, Johnson and Stewart (1971) concluded:

“Our findings suggest that hyperactive children are generally behaving in a normal way by the time they enter their teens. They are less active, distractible, impulsive, and excitable than they were in grade school, though these symptoms are still troublesome” (Mendelson et al. 1971, p. 277).

However, despite historical tendencies to conceptualize ADHD as a childhood disorder, the past 20 years have witnessed a substantial increase in research on ADHD in adolescents and adults. For example, in the introduction to his book-length treatment of adult ADHD, Wender (1995) stated:

“During the past decade researchers have become convinced that ...ADHD...is a common psychiatric disorder in adults” (Wender 1995, p. 3).

A closer look at the historical literature on ADHD shows that the idea that ADHD can exist in adults is not new. As long ago as 1902 researchers noted the developmentally chronic nature of ADHD and longitudinal studies began appearing in the 1970s (Pontius 1973, Still 1902). For example, in 1902 George Still believed that this “major defect in moral control” so typical of ADHD cases was relatively chronic. While it could arise from an acquired brain defect secondary to an acute brain disease, and might remit on recovery from the disease, in most cases it was chronic (Still 1902). Similarly, in 1973, Anneliese Pontius summarized her clinical observation of more than 100 adults with Minimal Brain Dysfunction (MBD). She proposed that many such adults demonstrated hyperactive and impulsive behaviour and that their disorder likely arose from frontal lobe and caudate dysfunction. This would lead to “an inability to construct plans of action ahead of the act, to sketch out a goal of action, to keep it in mind for some time (as an overriding idea) and to follow it through in actions under the constructive guidance of such planning” (p. 286). Pontius went on to show that indeed adults with MBD demonstrated such deficits, indicative of dysfunction in this brain network (Pontius 1973).

However, it was only as a consequence of several neuroimaging studies two decades later that ADHD (hyperactivity) became recognised in clinical and scientific journals as a valid psychiatric disorder of adulthood distinct from other diagnostic conditions (Spencer et al. 1994). These studies demonstrated that hyperactive adults manifested reduced glucose metabolism globally and particularly in the premotor cortex and superior prefrontal cortex, areas previously shown to be instrumental in the control of attention and motor activity. Other studies showed that adults with ADHD had a reduced size in the prefrontal-caudate network similar to children with ADHD (Zametkin et al. 1990).

2.1.8 Changes with age

As would be expected with a developmental disorder, ADHD is associated with a clear age-dependent decline in symptoms. However, it has long been known from clinical follow-up studies that symptoms of inattention are more likely to persist into adulthood than symptoms of hyperactivity or impulsivity (Wilens et al. 2004). Disorganisation, impaired concentration and poor planning as well as impulsivity frequently remain as disruptive symptoms (McArdle

2004). Even when symptoms are not prominent enough to prompt a diagnosis, they are frequently associated with clinically significant impairments (Adler and Chua 2002).

The problems associated with ADHD appear in different ways at different ages, as the individual matures and as the environmental requirements for sustained self-control increase (Taylor and Sonuga-Barke 2008). Wender (1995) first drew attention to the continued adult form of ADHD and specifically to frequently associated features and subjective symptoms also seen in adults. These included affective lability, hot temper (with explosive and short-lived outbursts), emotional over-reactivity (leading to poor tolerance of stress), and disorganisation. Indeed, research suggests that the core childhood symptoms shift with development sometimes dramatically: hyperactivity often declines by adolescence, attentional problems appear to remain more constant, and impulsivity may transform into more overt difficulties in executive functions (Wender 1995).

Hyperactivity in a pre-school child may involve incessant and demanding extremes of activity. During the school years an affected child may make excess movements during situations where calm is expected rather than on every occasion and during adolescence hyperactivity may present as excessive fidgetiness rather than whole body movements. Finally, in adult life ADHD may manifest itself as a sustained inner sense of restlessness. Inattention too may diminish in absolute terms, and attention span usually increases with age; nevertheless it tends to lag behind that of unaffected people, and is not at the level that is expected and needed for everyday attainments. Inattentive symptoms remain prominent and clinically significant for almost all individuals presenting to clinics in adulthood, whereas hyperactive/impulsive symptoms are less prevalent (Millstein et al. 1997). Millstein and colleagues (1997) noted that 90% of adults presenting to their clinic showed inattentive symptoms, although the most common diagnosis remained the combined type (56%) with 37% receiving inattentive and 2% hyperactive/impulsive diagnoses (Millstein et al. 1997).

Hyperactivity

For many individuals with ADHD, restlessness transitions from psychomotor agitation (overt hyperactivity) to a sense of internal restlessness (Weiss et al. 1999). Overt symptoms such as fidgeting with hands or standing up in situations where sitting is expected become less tolerated and seen as more socially unacceptable in adulthood than they were in childhood. Likewise, adult work roles often require sitting for long periods of time which may be

particularly difficult for a person with ADHD. Not only can hyperactivity impact negatively on the workplace but also personal relationships where hyperactivity can affect friendships and romantic relationships, as individuals with ADHD may be less eager to engage in relaxing activities than their friends or family. Weiss et al (1999) suggested that increasing pressures to reduce overt hyperactivity in adulthood may lead to a significant increase in anxiety and other mood disorders in people with ADHD as they struggle to cope with their hyperactivity as adults (Weiss et al. 1999).

Inattention

Many adults with ADHD experience challenges in their workplace and daily functioning because of their inattentive symptoms (Nadeau 2005). Such symptoms, which may not have been the most disabling aspect of the disorder for individuals when they were children, can present serious difficulties at work. Adults with ADHD often struggle to meet deadlines, organize materials, prioritize tasks, and manage their time (Weiss et al. 1999). Such impairments can have serious consequences in terms of educational attainment and career advancement. High-functioning adults with ADHD are often able to progress through their initial schooling because of their intelligence, but as environments become more demanding, the disorder can limit their achievement (Nadeau 2005).

Inattention may severely affect a person's self-esteem and cause severe distress, particularly in certain situations. Several studies have shown that people with developmental disorders may become particularly aware of their symptoms when they enter challenging environments, such as starting university or a new job. With increasing age, in further education and/or the workplace, young people are expected to take greater personal responsibility for structuring and organising their time, prioritising tasks and meeting deadlines. Increasing age, also involves having to make important decisions about their future, yet, as Young and Gudjonsson (2005) noted, compared with their peers, young people with ADHD are less likely to make plans (Young and Gudjonsson 2005). People with ongoing symptoms of ADHD in adulthood may thus find the changes that often accompany the transition to adulthood particularly difficult as they may struggle to cope with their symptoms and while being expected to conform to what is expected of them as adults (Nadeau 2005).

Impulsivity

Just as inattention may present a more serious difficulty for adults with ADHD than for children with the disorder, symptoms of impulsivity can also have serious consequences. Adults with ADHD may find themselves ending jobs or relationships suddenly and against their better interests. They may also make unfortunate financial decisions, including impulsive shopping. They often have limited abilities to manage frustration and often become angry easily, but may express their anger inappropriately (Weiss et al. 1999). Moreover, others often label them unsympathetically as “lazy”, “stupid” or just “difficult” as they do not recognise these behaviours as caused by genuine cognitive impairments (Asherson 2005). These experiences can result in self-blame and exacerbate the problems with self-esteem that are experienced by many individuals with ADHD (Murphy and Barkley. 1996).

To summarise so far, ADHD is a common developmental disorder which frequently persists into adulthood and which involves core symptoms which are often severely impairing for those affected. It is also associated with comorbid psychiatric disorders which are likely to increase the burden and distress of young people with ADHD and their families, all of which imply a strong reason for its identification and treatment. A review of the literature of comorbid psychiatric problems associated with ADHD will follow next.

2.1.9 Comorbidities

Studies have consistently shown that young adulthood is a critical period for mental health. Mental disorders such as anxiety disorders, mood disorders, and substance use disorders often first emerge during adolescence or young adulthood (Kessler et al. 2007). National mental health surveys indicate that young people in the age range 15 to 24 have the highest rate of mental disorders (Andrews et al. 2001, Bijl et al. 1998, Kessler et al. 1994). Young adults are particularly at risk for alcohol use disorders (Bijl et al. 1998), although there is also some evidence for an increased risk of anxiety disorders (Alonso et al. 2004). Furthermore, depression among adolescents and young adults is of particular concern, given its link to suicide. Indeed, depression has been found to be the strongest single risk factor for attempted or complete suicides in adolescents and young adults (Beautrais et al. 1996).

Young adulthood is also a critical period of the lifespan. In this period of life many important steps are made that set the stage for future economic and social position, such as finishing

education, entering employment and starting a family. Because young adulthood is such a critical phase of socialization, poor mental health during this period of life may have particularly long-lasting adverse consequences (Newman et al. 1996). Indeed, Wittchen and colleagues (1998) found that mental disorders in young adults cause significant psychosocial impairments, limiting educational ability, work, and social interaction (Wittchen et al. 1998). Since the stakes for good mental health are high in young adulthood, it is important that young adults with mental health problems seek appropriate help early.

Treatments for mental disorders in young people have significantly improved over recent decades, and include better pharmacological treatments and more effective psychosocial interventions (Patel et al. 2007). Several meta-analyses have shown support for the effectiveness of pharmacotherapies and psychotherapies, for various mental disorders in both adolescent and adult populations, including internalizing disorders such as anxiety disorder and externalizing disorders such as ADHD (Faraone et al. 2004, Malouff et al. 2007, Mitte 2005, Prendergast et al. 2006).

It has long been known that adults with a history of childhood ADHD have a comparatively high prevalence of other mental disorders that develop subsequent to ADHD and may to some extent be caused by the long-term effects of trying to cope with primary ADHD symptoms (Biederman 2004). Biederman and colleagues (1991), in their systematic review of comorbidity of ADHD among those aged 4-33 years, estimated that as many as 65% of children and adolescents with ADHD will have one or more comorbid psychiatric or other disorders and more than 80% of adults with ADHD will have at least one other disorder (Biederman et al. 1991). Antisocial personality disorder, alcohol misuse, substance dependence, depression and anxiety disorders are very common in this group (National Institute for Clinical Excellence 2008). Also, ADHD is a common comorbidity for individuals with learning disability (Buckley et al. 2006).

The following section will now review the literature regarding comorbidities among those with ADHD.

Depression and other mood disorders among those with ADHD

Depression and other mood disorders have been found to be significantly higher in people with ADHD. Anxiety rates are typically reported to be in the range of 30-45% (Busch et al.

2002, Ghanizadeh et al. 2008, The MTA Cooperative Group 1999). Rates vary across studies and by whether “any anxiety disorder” or specific types (e.g. separation anxiety disorder) are reported. For example, about one in four children with ADHD were diagnosed with one or more of the anxiety disorders (Tannock and Brown 2000).

Studies suggest that mood disorders may increase as the person grows into adulthood. Kessler and colleagues (2006) conducted the US National Comorbidity Replication Survey and found that 38% of adults with ADHD also had a mood disorder compared to 11% of adult respondents without ADHD (Kessler et al. 2006). Biederman and colleagues (1993b) also found that nearly one third (31%) of adults they managed for ADHD met full diagnostic criteria for major depressive disorder and over half (52%) of adults referred with ADHD met criteria for two or more major anxiety disorders (Biederman et al. 1993b).

In addition to anxiety and mood disorders, a recent study of 141 adults with ADHD found that 95% had mood symptoms, chiefly mood instability (Kooij et al. 2001) - a condition characterised by excessive emotional reactions and frequent mood changes (Weiss et al. 1999). Mood dysregulation is thought to represent a core impairment in adult ADHD and may be related to the same processes that cause dysregulation of other executive processes (Asherson et al. 2007). This may explain why adults with ADHD and mood instability have been frequently reported to respond to stimulants over the same time as core ADHD symptoms (Asherson et al. 2007).

Antisocial behaviour and criminality among those with ADHD

There is increasing recognition that ADHD is associated with antisocial behaviour and criminality (Babinski et al. 1999, Barkley et al. 2004, Barkley 2009, Biederman et al. 1992, Langley et al. 2010, Taylor et al. 1996, Young and Gudjonsson 2008). Biederman and colleagues (1992) found that 33-50% of people with ADHD met criteria for ODD (Biederman et al. 1992).

Early onset and persistent antisocial behaviour is commonly associated with ADHD (Barkley et al. 2004, Barkley 2009, Langley et al. 2010). Only five follow-up studies exist that have examined for antisocial behaviour in children diagnosed with ADHD in young adulthood and which had large clinic-referred samples in addition to control groups and had retained at least 50% or more of their original samples into adulthood (Barkley et al. 2004, Mannuzza et al.

1993, Rasmussen et al. 2001, Satterfield and Schell 1997, Weiss and Hechtman 1993). Rasmussen & Gillberg (2001) and Satterfield & Schell (1997) both found that criminal arrests were higher among hyperactive children followed up to adulthood (Rasmussen et al. 2001, Satterfield and Schell 1997) than those of their control groups.

The study by Barkley and colleagues (2004) which followed a relatively large sample of clinically referred hyperactive children and a community group for an average of more than 13 years into early adulthood and who at follow up had a mean age of 21, found that hyperactive children were more likely to engage in a variety of antisocial activities and did so more often, in most cases, than did the control group. These activities were largely drug-related and the frequency of such activities was largely predicted by severity of ADHD in childhood, adolescence and adulthood, with the latter contributing to risk beyond severity of disorder at the earlier developmental period (Barkley et al. 2004). Barkley's longitudinal study showed that ADHD independently predicted the development of antisocial behaviour (a developmental trajectory thought to be mediated by familiar environmental influences) a finding supported by other studies (Babinski et al. 1999, Taylor et al. 1996). However, the mechanisms by which ADHD leads to antisocial behaviour are not clear.

The association between ADHD and crime is becoming increasingly recognised and regarded with concern. Studies conducted in the US, Canada, Sweden, Germany, Finland and Norway suggest that around two thirds of those in young offender institutions, and up to half of the adult prison population, met criteria for ADHD in childhood and many continued to be symptomatic (Davren 2007, Rosler et al. 2004). For example, Rosler and colleagues (2004) using the Wender Utah Rating Scale (WURS) and the Eysenck Impulsivity Questionnaire (EIQ) to evaluate the prevalence of ADHD, reported that the overall prevalence of ADHD of the young male inmates in their study was 45% according to DSM-IV criteria (Rosler et al. 2004). Young and Gudjonsson (2008) found that a group of individuals in remission from ADHD symptoms reported significantly lower levels of antisocial behaviour in the last year, suggesting that criminal behaviour may be directly linked to symptoms, reflecting poorly planned or impulsive behaviour and opportunistic crimes or violent outbursts (Young and Gudjonsson 2008).

Barkley (2009) found that the most common forms of antisocial activity for the adults with ADHD were shoplifting (53%), followed by assault (35%) and illegal sale of drugs (21%).

He hypothesised that it was problems related to ADHD that contributed most to antisocial behaviour such as childhood conduct problems, teen antisocial activity, drug use and low education rather than the severity of ADHD (Barkley 2009). The view that ADHD symptoms per se are not related to antisocial behaviour was also held by Hodgins (2007) who after reviewing persistent violent offending concluded that although ADHD is highly related to CD and this disorder in turn is highly related to criminality, it is the callous-unemotional traits and not ADHD symptoms that are associated with aggression and delinquency (Hodgins 2007). This conclusion is further strengthened by the finding that boys with such traits without ADHD have been shown to have the considerably higher rates of aggressive behaviour and delinquency compared to boys with ADHD (Frick and Marsee 2006).

Alcohol and drug misuse among those with ADHD

Several studies have found that ADHD symptoms are also associated with later drug and alcohol misuse and that these may influence the high prevalence rates of antisocial behaviour and criminality among young people and adults with ADHD described above. For example, Kessler and colleagues (2006) found that 15% of their ADHD sample had a substance misuse disorder and that this was significantly higher than among those who did not have ADHD (Kessler et al. 2006). Mannuzza and colleagues (1993) who followed up 91 white males (mean age, 26 years), diagnosed as hyperactive in childhood, and 95 of comparison cases of similar race, gender, age, whose teachers had voiced no concerns about their school behaviour in childhood, found that those diagnosed with ADHD in childhood had significantly higher rates than comparisons of drug abuse disorders (16% versus 4%). The authors noted that when this sample was assessed in adolescence these disturbances were dependent on the continuation of ADHD symptoms, however, in adulthood, drug disorders appeared, in part, independent of sustained ADHD (Mannuzza et al. 1993).

Barkley and colleagues (2009) also found greater risk for alcohol use disorders in those with ADHD; however, the level and type of drug use disorder may be more related to comorbid disorders such as CD and antisocial personality disorder than to ADHD per se (Barkley 2009). Wilens (2007) observed that previous studies have shown that adults with substance misuse and a history of childhood ADHD tend to have earlier onset of substance misuse relative to adults without ADHD (Wilens 2007), including a greater sensitivity to cocaine misuse (Carroll and Rounsaville 1993).

This high prevalence of substance misuse in people with ADHD may stem from an attempt to self-medicate. Mannuzza and colleagues (1989) suggested a progression from ADHD to CD and then to substance misuse which they hypothesised was related to demoralisation and failure (Mannuzza et al. 1989). Recent reports and reviews by Wilens and colleagues (1998; 2004; 2007) also suggested a strong relationship between ADHD and self-medication with drugs; between 35% and 71% of adults with alcohol dependence disorder had childhood-onset and persistent ADHD (Wilens et al. 2004, Wilens 2007) and 15-25% of adults dependent on alcohol and other substances have current ADHD (Wilens et al. 1998). In addition, studies have highlighted that the consequences of substance misuse in those with ADHD can be severe, with one study reporting that 24% of inpatients in a substance misuse treatment facility had ADHD (Schubiner et al. 2000).

2.1.10 Impairments in daily activities among those with ADHD

At all levels of severity, these and other comorbid psychiatric disorders associated with ADHD create an additional burden for individuals and families affected by ADHD. Along with core symptoms of ADHD (e.g. inattention, hyperactivity and impulsivity) comorbidities are likely to negatively impact on school performance, employment, physical health, family and home life, and quality of life (Barkley 2009). Indeed, it is increasingly recognised that negative outcomes can arise as secondary to the ADHD symptoms of hyperactivity, impulsivity and poor attention. Poor academic attainment, learning difficulties, poor peer relations and low self-esteem are formally recognised as secondary symptoms of ADHD, rather than comorbidities (Pliszka 1998). For example, Pliszka (1998) noted that at least some of the specific reading difficulties experienced by children with ADHD may be indirectly attributable to their symptoms (Pliszka 1998). When those with ADHD who have reading disabilities are treated with methylphenidate, improvements are seen in their reading ability scores (Richardson et al. 1988).

Two observational studies, recently published in a book by Russell Barkley (2009) have added to our knowledge of the problems facing adults with ADHD (Barkley 2009). These are the UMASS study (conducted at the University of Massachusetts) and the Milwaukee study (conducted at The Medical College of Wisconsin in Milwaukee). Both studies aimed to observe secondary outcomes of patients living with ADHD such as: educational and occupational functioning; drug use and antisocial behaviours: health, lifestyle, money

management and driving; sex, dating, marriage, parenting and psychosocial adjustment of offspring; and neurological functioning. These studies showed that adults with ADHD, when compared to a control group, in addition to being more likely to use certain illicit drugs and to engage in certain antisocial behaviour, were also more likely to have significant problems with money management (Barkley 2009).

Specifically, the UMASS study which examined lifestyle outcomes among three cohorts of adult patients - 146 clinic-referred adults with ADHD, 97 adults seen at the same clinic who were not diagnosed with ADHD, and also a third general community sample of 109 adults without ADHD - found that 67 percent of adults with ADHD compared to the control group (15 percent) had trouble managing money. This finding was also found in the Milwaukee study, an ongoing study since 1977 (with the most recent follow-up conducted from 1999 to 2003). The Milwaukee study examined the secondary lifestyle outcomes of 158 children who had been diagnosed with ADHD and, as adults, either continue to experience symptoms or no longer have the disorder at the age of 27, compared to a community control group of 81 children without ADHD who were followed concurrently (Barkley 2009).

Poor adolescent ADHD and antisocial outcomes were also reported by Ford and colleagues in their follow-up study described in section 2.1.6 (Ford et al. 2008). The authors reported that most adolescents in their study, aged 11 to 20 years, exhibited high levels of antisocial behaviour, criminal activity and substance use problems suggesting that adolescents, who were clinically recognised, treated and met diagnostic criteria for ADHD in childhood show poor adolescent ADHD and antisocial outcomes (Ford et al. 2008).

The UMASS and Milwaukee studies described above have also highlighted the multitude of difficulties in education experienced by people with ADHD. Barkley (2009) showed that adults with ADHD had experienced more adversities with their education than those without ADHD. For example, adults with ADHD frequently reported having been retained in grade, received special education, and been diagnosed with learning disabilities or behavioural disorders while in compulsory schooling compared to those without the disorder. On tests of educational achievement given in Barkley's projects, the ADHD groups were poorer in their arithmetic, spelling, and reading and listening comprehension skills than were adults in the control groups. They also had a higher comorbidity of specific learning disabilities (Barkley 2009). Previous studies have also shown that children with ADHD are more likely to be

suspended and expelled than their peers (August et al. 1983, Barkley et al. 2006, Lambert 1988) and are more likely to attend special schools (Lambert 1988), or repeat a grade compared with their healthy peers (Barkley et al. 2006). Such findings recently led Barkley (2009) to conclude that of all domains of major life activity, the domain in education is the most pervasively affected in adults with ADHD (Barkley 2009).

High-risk taking characteristics associated with ADHD may also put adolescents and young adults with ADHD at increased risk of poorer outcomes in other areas too (Barkley 2009). Studies have reported that adults with ADHD are more likely to have car accidents than adults without the disorder (Barkley et al. 1996a) and are more likely to lead riskier sexual lifestyles than those who do not have ADHD (Barkley 2009, Saylor et al. 2010). In regards to the latter, a recent longitudinal study of ADHD found that those who had grown up with ADHD were more likely to have contracted a sexually transmitted disease and were more likely to have become pregnant by age 21 than community controls (Barkley 2009).

Core symptoms of ADHD are also associated with impairments in occupational functioning. As discussed in section 2.1.7, adults with ADHD often struggle to meet deadlines, organize materials, prioritize tasks, and manage their time (Nadeau 2005, Weiss et al. 1999). Adults with ADHD often experience problems such as getting along with others, demonstrating behaviour problems, being fired, quitting out of boredom, and being disciplined by supervisors at a higher rate than those without ADHD (Barkley 2009). Growing up as a child with ADHD is also associated with lower job status, and fewer current working hours per week regardless of its persistence into adulthood (Barkley 2009).

Such and other comorbid problems associated with adult ADHD may also help to explain the greater incidence of marital dissatisfaction that has been shown in adults with ADHD. Adults with ADHD tend to have more marital problems as well as poorer quality of dating relationships than those without ADHD (Barkley 2009). Spouses of adults with ADHD have also been shown to be significantly less satisfied in the marriage than spouses in research control groups (Barkley 2009).

The problems associated with ADHD and the wide ranging consequences that these are likely to have on psychosocial functioning, have led some authors to suggest that low self-esteem is a feature of adults with ADHD (Jackson and Farrugia 1997, Murphy 1995, Rucklidge et al. 2007). Murphy (1995) noted that adults with ADHD often have strong feelings of

incompetence, insecurity and ineffectiveness and a chronic sense of underachievement and frustration (Murphy 1995). Jackson and Farrugia (1997) suggested that this results from problematic educational experiences and interpersonal difficulties (Jackson and Farrugia 1997). Moreover, Rucklidge and colleagues (2007) found that adults with ADHD are more likely to have an “inter-uncontrollable attributional style” compared with controls, whereby recall of negative life events in childhood are interpreted as the results of personal characteristics rather than forces beyond their control (Rucklidge et al. 2007).

2.2 Chapter summary

Several studies have shown the severity and complexity of ADHD in adolescence and adulthood. Young people with ADHD are likely to present more frequently with a variety of comorbid psychiatric problems which add to the burden experienced by this group. There is also evidence that ADHD is associated with significant impairments in daily activities and that these may develop secondary to the effects of having to struggle with the core symptoms of ADHD. However it is unclear to what extent impairments may be more directly associated with comorbidities related to ADHD.

The next chapter will review the current policies and guidelines that exist with regard to the management and care of ADHD and the transition from child to adult health services, followed by a review of how well these guidelines are being implemented in practice in the UK.

CHAPTER 3

Management and care of ADHD: Policy and practice

3.1 Introduction

The aim of this chapter is to give an overview of some of the key policy recommendations and clinical guidelines related to the diagnosis and management of ADHD and then to review how ADHD is currently being managed in practice. As the second and third research aims of this study were to investigate health service use and healthcare transition among young people with ADHD, a review of policy relating to healthcare transitions is then given before examining how this is currently managed in practice. Literature searches for this review involved a variety of sources including peer-reviewed journals, reports, book chapters, policy documents and unpublished literature. Searches were made of a number of websites such as those of health-related organisations (e.g. the King's Fund, the UK Department of Health). Broad search terms were used (e.g. "attention deficit hyperactivity disorder", "transition") to maximise retrieval of relevant literature. Where possible, the review explores research conducted within the last ten years. To keep it as relevant as possible to the aims of this thesis, the literature searches were primarily concentrated on health rather than social or education services and were focused on the UK, although reference is made to social, education and international research where it is thought to have particular bearing.

3.2 Guidelines relating to ADHD

Various clinical guidelines relating to the diagnosis and management of ADHD have been published. A recent systematic review of national and international clinical guidelines of ADHD (Seixas et al. 2012) identified thirteen guidelines published between May 2000 and January 2011 by ten different national and international medical associations including: the *American Academy of Pediatrics* (American Academy of Pediatrics 2000, American Academy of Pediatrics 2001), the *New Zealand Ministry of Health* (NZ 2001), the *Deutsche Gesellschaft für Psychiatrie, Psychotherapie und Nervenheilkunde* (Ebert et al. 2003), the *European Society for Child and Adolescent Psychiatry* (Banaschewski et al. 2006, Taylor et

al. 2004), the *British Association of Psychopharmacology* (Nutt et al. 2007), the *American Academy of Child and Adolescent Psychiatry* (Greenhill et al. 2002, Pliszka 2007), the *Deutsche Gesellschaft für Kinder und Jugendpsychiatrie und Psychotherapie* (Deutsche Gesellschaft für Kinder und Jugendpsychiatrie und Psychotherapie 2007), the *National Institute for Health and Clinical Excellence* (National Institute for Clinical Excellence 2008), the *Scottish Intercollegiate Guideline Network* (Scottish Intercollegiate Guideline Network 2009), and the *Canadian Attention Deficit Disorder Resource Alliance* (Canadian Attention Deficit Disorder Resource Alliance 2011).

Notably, all thirteen guidelines included in the review make recommendations for ADHD in childhood and adolescence; however, only two cover ADHD from childhood to adulthood (Seixas et al. 2012). These include the most recent NICE guidelines, published in the UK in September 2008, and the recently published guidelines by the Canadian Attention Deficit Disorder Resource Alliance (CADDRA) (Canadian Attention Deficit Disorder Resource Alliance 2011, National Institute for Clinical Excellence 2008). In addition, two further guidelines have provided recommendations for the management of ADHD in adolescents and adults including those published by the British Association for Pharmacology in 2007 (Nutt et al. 2007) and the guidelines published by the European Network Adult ADHD in 2010 which, although not included in the review by Seixas and colleagues, focused solely on adults (Kooij et al. 2010).

Since this thesis addresses health service use among adolescents and young adults who live in England, this chapter draws heavily upon the UK guidelines, and in particular the most recent guidelines provided by NICE (National Institute for Clinical Excellence 2008). These were published approximately six months before the data collection for this study began and were recently (November 2011) reviewed by the registered stakeholders who pushed forward the next date of review to July 2014 (National Institute for Clinical Excellence, 7th January 2013). The role of NICE is to provide guidance, set quality standards, and monitor health outcomes through a national database. It makes recommendations to the NHS on new and existing medicines, treatments and procedures, treating and caring for people with specific diseases and conditions. It also makes recommendations to the NHS, local authorities and other organisations in the public, private, voluntary and community sectors on how to improve people's health and prevent illness and disease. As NICE is concerned with both effectiveness in treatments, and cost-effectiveness in the implementation of these treatments,

the use of NICE guidance can help service providers cut costs while at the same time maintaining and improving services (Rawlins and Culyer 2004). It is intended that the role of NICE will be extended to social care in April 2013 as a result of the Health and Social Care Act introduced in 2012 (NICE, 7th January 2013).

3.2.1 Diagnosis of children with ADHD

The use of categorical diagnostic criteria in the diagnosis of ADHD, mostly either DSM-IV or ICD-10 is unanimously recommended by all the clinical guidelines (Seixas et al. 2012). The NICE (2008) guidelines, for example, state that ADHD should be diagnosed when all of the following three conditions apply: (i) The symptoms of inattention, hyperactivity and impulsivity meet the criteria for ADHD in the DSM-IV (or for hyperkinetic disorder in the ICD-10); (ii) the impairment is at least of moderate clinical and/or psychosocial significance; and (iii) the apparent symptoms of ADHD are pervasive (National Institute for Clinical Excellence 2008). The second condition means that the level appropriate to the child's chronological and mental age has not been reached in several domains (for example, achievement in schoolwork or homework; dealing with physical risks, and avoiding common hazards; forming positive relationships with family and peers; developing a positive self-image; and avoiding criminal activity). The third condition refers to symptoms that are occurring in two or more settings such as in the home, school, or workplace.

There is also a general consensus that the diagnosis of ADHD should be based on a comprehensive assessment by a child and adolescent psychiatrist or a paediatrician of the person's needs; coexisting psychiatric conditions; social, familial, and educational, and/or occupational circumstances; physical health, and, for children and young people, their parents' or carers' mental health (Seixas et al. 2012). Essential components of a full assessment process include a clinical interview, a medical examination and administration of rating scales to parents and teachers (for example, by self-report). Other components such as direct observation in educational settings or cognitive, neuropsychological, developmental and literacy skills assessments may or may not be indicated.

Clinical interview

A clinical interview is commonly viewed as the "gold standard" of assessments for ADHD (Seixas et al. 2012). For example, NICE (2008) recommends that a clinical interview be

carried out by a paediatrician, psychiatrist, clinical psychologist or specialist nurse; usually in a semi-structured format so that key issues can be systematically investigated. The chief aim of the interview is to detail the full range of problems and their history, together with family, health, social, educational and demographic information. The interview is also designed to highlight any additional, more specialist, assessments that might be required to facilitate diagnosis and intervention planning. If significant comorbidity is found, a referral to an educational or clinical psychologist and/or social worker should be considered. Frequently, a family interview is recommended for children where persons other than the child are involved to provide additional information and perspectives (National Institute for Clinical Excellence 2008).

Medical assessment

A further recommendation relates to the exclusion of physical comorbidity as part of the assessment of ADHD (Seixas et al. 2012). A specialist clinical assessment by a psychiatrist or paediatrician is generally recommended for those referred for an ADHD assessment (Seixas et al. 2012). One aim is to rule out undiagnosed disorders, with symptoms that in rare instances may mimic or cause some aspects of ADHD, such as hearing impairment, epilepsy, thyroid disorder and iron deficiency anaemia. The possible contribution of prenatal (e.g. pregnancy related) and perinatal factors (e.g. factors that affect the period immediately before or after birth) that are known to increase the risk of development of ADHD symptoms is noted and the assessment identifies physical signs of certain genetic conditions that have an increased risk of ADHD. There may also be other coexisting physical, neurological and developmental disorders that need to be identified which will then shape later management.

Standardised rating scales

In conjunction with a clinical interview and a medical assessment, the use of rating scales is generally viewed as a way of improving and standardizing the reliability, breadth and efficiency of assessments. However, as Seixas and colleagues noted (2012) the role of rating scales has received a different emphasis in different guidelines. These are described as auxiliary diagnostic tools, as cost-effective methods of obtaining collateral information and as systematic outcome measures to demonstrate treatment outcome (Seixas et al. 2012). An example of a frequently used rating scale in ADHD is the Barkley Scales which comes in an informant and a self-report version (Barkley and Murphy 1998, Conners and Barkley 1985).

This scale measures 18-symptom items for ADHD from DSM-IV-TR that are scored from 0 (never or rarely) to 3 (very often). A total score is derived from adding symptom scores across the 18 items. Diagnosis of ADHD in childhood has traditionally been based on parental/informant reports on hyperactivity.

Educational and occupational adjustment

An understanding of a child or young person's adjustment at school, or functioning in the workplace is also considered an important part of an assessment for ADHD (National Institute for Clinical Excellence 2008). In addition to providing information gathered by questionnaire, teachers may be asked to provide specific information on social and academic functioning. If there are particular problems with functioning at school, direct observation by the assessing clinicians of behaviour in the classroom and in other, less structured situations, may be undertaken.

Psychological and psychometric assessment

Lastly, the importance of screening for comorbidities is also emphasised in all the guidelines (Seixas et al. 2012). As symptoms of ADHD can overlap with symptoms of other related disorders it is often necessary to assess other psychiatric conditions. Common coexisting conditions in children with ADHD are disorders of mood, conduct, learning, motor control and communication, as well as anxiety disorders.

Educational and clinical psychologists may undertake further assessments if learning difficulties, including poor literacy skills, dyslexia, or other problems such as dyscalculia or non-verbal learning difficulties, are suspected. These assessments may help to explain the presence of attentional problems, even if ADHD is present as well, as such problems will need addressing as part of the management plan. Intellectual status needs to be understood so that therapy can be designed to be developmentally appropriate. Cognitive impairments involving memory, problem-solving and attention are also very likely to be present and ideally should be investigated further by clinical or educational psychologists. Family-based psychosocial interventions of a behavioural type (such as social skills training or parent behavioural management training) are recommended for treatment of comorbid behavioural problems.

3.3 Management of school- aged children and young people with ADHD following diagnosis

The provision of treatments and interventions for children and young people with ADHD depends on the severity of symptoms, impairments, needs and preferences although it should usually encompass drug treatment and/or psychological interventions. Notably, NICE's (2008) guidelines divides recommendations for the treatment of school-aged children and young people (ages 11 to 18) into those with moderate and severe ADHD (Appendices I-J gives a detailed summary of these recommendations for each of these groups respectively).

Drug treatment

Seixas and colleagues (2012) noted that there is a high level of agreement concerning which drugs should be offered to young people with ADHD. NICE (2008) and the other twelve published guidelines included in their review recommend that the prescription of stimulant (Methylphenidate and Dexamphetamine) medication should be the first line treatment for those with severe ADHD (Seixas et al. 2012). This is due to the finding of several scientific studies that stimulants exert a positive effect on the biological and cognitive processes that are thought to cause ADHD (Jadad et al. 1999). Notably, other drugs, such as bupropion, clonidine, guanfacine, and tricyclic antidepressants were recommended by NICE for patients who failed other treatments or who suffered significant comorbidity, albeit not as a first-line option (National Institute for Clinical Excellence 2008). CADDRA (2011) is the only guideline that makes a recommendation for the recently licensed lisdexamfetamine. In addition, the noradrenaline reuptake inhibitor atomoxetine is a recognised treatment option in most guidelines (Seixas et al. 2012). Furthermore, despite antipsychotics receiving three positive recommendations, both NICE and the New Zealand Ministry of Health guidelines advise against the use of antipsychotics like risperidone, which is recommended by the International Consensus Statement on Management of ADHD and Aggression (Kutcher et al. 2004) - a document not included in the systematic review by Seixas and colleagues (2012).

The guidelines generally recommend that drug treatment for ADHD should only be initiated by an appropriately qualified healthcare professional with expertise in ADHD and should be based on a comprehensive assessment and diagnosis (National Institute for Clinical Excellence 2008). Once drug treatment has been initiated, drug therapy may be monitored by general practitioners, under shared care arrangements, who can continue to prescribe the

medication. Furthermore, monitoring of measurements of height and weight, blood pressure and pulse rate should be an ongoing feature following the initiation of drug treatment (National Institute for Clinical Excellence 2008).

However, although there is a high level of agreement among the guidelines on drug treatment for children and young people with ADHD, there are also notable international differences. The most obvious difference may be seen in the recent NICE Guidelines for children and young people where medication treatment is only recommended for severe cases, whereas the US guidelines recommend that medical treatment should also be offered to those cases that are mild (AAP, 2001). Indeed, NICE recommends that drug treatment should not be indicated as the first-line treatment for all school-age children and young people with ADHD but should be reserved for those with severe symptoms and impairment (or for those with moderate levels of impairment who have refused non-drug interventions, or whose symptoms have not responded sufficiently to parent-training/education programmes or group psychological treatment) (National Institute for Clinical Excellence 2008).

Psychological treatments

Optimal management of ADHD is generally thought to involve a combination of drug and psychological treatments although there is considerable disagreement regarding which specific psychological interventions should be provided. For example, NICE (2008) gives explicit recommendation for school-based interventions, behavioural parent training, psychoeducation, carer support, individual and group interventions, family-based interventions, behavioural management, social skills training, CBT and self-help whereas the American Academy of Pediatrics (American Academy of Pediatrics 2001) only explicitly recommends school-based interventions, behavioural parent training, psychoeducation and carer support (American Academy of Pediatrics 2001, National Institute for Clinical Excellence 2008). One explanation for this may be that the evidence base for the use of certain interventions such as CBT in children with ADHD is still not strong, especially when considering the evidence base for other interventions such as psychoeducation. Psychoeducation has consistently been shown to help to empower the patient with knowledge about the disorder, its impacts and how to function optimally while having ADHD (Canadian Attention Deficit Disorder Resource Alliance 2011). Indeed, the guidelines by the British Association for Psychopharmacology, published in 2007 for adults with ADHD,

recommended that general psychotherapeutic support to the individual, family and others is helpful, particularly around the time of diagnosis and treatment initiation stating that this frequently helps to inform the individual about the condition and prognosis whilst helping the individual to adopt positive coping strategies to deal with their ADHD and ADHD related symptoms in addition to preventing negative effects on self-esteem or unrealistic expectations of treatment (Nutt et al. 2007).

NICE further makes explicit recommendations for teachers and parents to receive training and education on ADHD. Specifically, it recommends that teachers who have received training about ADHD and its management should provide behavioural interventions in the classroom to help children and young people with moderate or severe ADHD. Similarly, if the child or young person with ADHD has moderate levels of impairment, parents or carers should be offered referral to a group parent-training/education programme, either on its own or together with a group treatment programme (CBT and/or social skills training) for the child or young person. This is advised as particularly important when children and young people with severe ADHD refuse drug treatment or it is not accepted by their parents or carers (although healthcare professionals are advised to inform parents or carers and the child or young person about the benefits and superiority of drug treatment in this group). If drug treatment is still not accepted, NICE (2008) recommends that a group parent-training/education programme (e.g. CBT and/or social skills training), during which particular emphasis should be given to targeting a range of areas, including social skills with peers, problem solving, self-control, listening skills and dealing with and expressing feelings. Active learning strategies should be used, and rewards given for achieving key elements of learning (National Institute for Clinical Excellence 2008).

Following successful treatment with a parent-training/education programme and before considering discharge from secondary care, NICE also recommends that the child or young person should be reviewed, with their parents or carers and siblings, for any residual problems such as anxiety, aggression or learning difficulties. Treatment plans should be developed for any coexisting conditions. Moreover, it stresses that the professional delivering parent training sessions or education programmes should consider contacting the school to provide the child's teacher with written information on areas of behavioural management covered during the session (National Institute for Clinical Excellence 2008).

As many people with ADHD suffer from comorbid psychiatric problems such as depression and substance use disorders the benefits of providing interventions towards alleviating these problems prior to the management of core ADHD symptoms should also be considered. For example, NICE (2008) recommends that severe substance use disorders should be treated first due to the known risks and impairments associated with such behaviour (National Institute for Clinical Excellence 2008) and the fact that ongoing substance misuse has been shown to interfere with evaluation of ADHD treatment response (National Institute for Clinical Excellence 2008). Although self-treatment with stimulants is infrequent according to NICE (2008) the use of alcohol and cannabis to dampen down symptoms associated with adult ADHD is common (National Institute for Clinical Excellence 2008).

Person-centred care

At the heart of the NICE guidelines is the emphasis on person-centred care. Treatment and care should take into account people's needs and preferences, and, in the case of children, those of their parents or carers. For example, in regards to the treatment of school-aged children and young people with ADHD, NICE advises that it is important to review each year whether the child or young person needs to continue drug treatment and to ensure that the long-term pattern of use is tailored to the person's needs, preferences and circumstances. All people with ADHD, including children, should have the opportunity to be involved in decisions about their care and treatment in partnership with their healthcare professionals. If people do not have the capacity to make decisions, healthcare professionals should follow the Department of Health guidelines – "Reference guide to consent for examination or treatment" (2001; available from www.dh.gov.uk). Healthcare professionals should also follow a code of practice accompanying the Mental Capacity Act 2005 (summary available from www.publicguardian.gov.uk). If the person is under 16, healthcare professionals should follow guidelines in "Seeking consent: working with children" (available from www.dh.gov.uk) (National Institute for Clinical Excellence, 2008).

Good communication between healthcare professionals and people with ADHD is also stressed as an essential component of care delivery. This, NICE recommends, should be supported by evidence-based written information tailored to the person's needs. Treatment and care, and the information people are given about it, should also be culturally appropriate and be accessible to people with additional needs such as physical, sensory or learning

disabilities, and to people who do not speak or read English (National Institute for Clinical Excellence 2008). NICE further notes that healthcare professionals should provide people with ADHD and their families or carers with relevant, age-appropriate information (including written information) about ADHD at every stage of their care. The information should cover diagnosis and assessment, support and self-help, psychological treatment, and the use and possible side effects of drug treatment.

If the person agrees, families and carers should have the opportunity to be involved in decisions about treatment and care. Families and carers should also be given the information and support they need, and be encouraged to become involved in interventions where appropriate (National Institute for Clinical Excellence 2008).

Multi-agency work

The need for multidisciplinary, multi-agency input into the diagnosis and management of neurodevelopmental disorders is reflected in a succession of health and education professional guidance documents. The National Service Framework (NSF) for Children, Young People and Maternity Services in England and Wales (Department of Health 2004) was set out with the aim to improve the mental health of all children and young people in England and Wales, and stated that this population segment should have access to timely, integrated, high-quality, multidisciplinary mental health services to ensure effective assessment, treatment and support. In particular, it recognised that multi-agency partnerships are essential to delivering coordinated services for children who are disabled, have mental health problems or who are otherwise in special circumstances (Department of Health 2004). Although the NSF no longer forms part of the Government's health policy, the principles set out in the NSF remain part of its overall policy objectives. On similar lines, the White Paper, "Healthy Lives, Healthy People; Our Strategy for Public Health", published in November 2010, highlighted the government's continuing commitment to developing a coherent approach to key transitional healthcare instead of tackling issues in isolation (Department of Health 2010b).

3.4 Guidelines and policy statements relating to the transition from child to adult health services

In the past two decades, healthcare transitions, that is, the process of moving from child to adult health services, has become a serious policy issue worldwide. Due to advances in medical technology and practice, many more young people who would have previously died in childhood are now living into their early adult years and beyond. As a result, many young people born with chronic conditions are making the transition from child to adult health services. This has placed pressure on health services to ensure good quality healthcare is maintained throughout the process. The finding that poorly managed transitions can have serious and wide ranging consequences has further raised the topicality of healthcare transition. If transition between child to adult health services is poorly managed, young people with ongoing needs are more likely to drop-out of treatment and follow-up, leading to an increased risk of poorer health and wellbeing and poor social, occupational and educational outcomes (American Academy of Paediatrics and Medicine. 2002, Department of Health 2008, Lamb et al. 2008, While et al. 2004).

Given the seriousness of providing adequate transitions, a range of guidelines on effective transitioning have been published in the UK (Department for Education and Skills 2007, Department of Health 2004, Department of Health 2006, Every Child Matters 2007, Commission for Social Care Inspection 2007, Department of Health 2008, Department of Health 2011c, Lamb et al. 2008), including the three best practice guidance on the transition from child to adult services recommended by the most recent NICE guidelines for ADHD: “Transition: getting it right for young people” (Department of Health 2006); “Growing up Matters” (Every Child Matters 2007) and “Transitioning: Moving on well” (Department of Health 2008) (see Appendix L for a detailed summary of NICE (2008) recommendations regarding transition from child to adult services for those with ADHD). Five key themes can be identified in these and other national and international policy statements and clinical guidelines relating to healthcare transition. These include (i) an emphasis on ensuring that transition takes place during the right time, (ii) the importance of informing and involving the young person and their family in the transition process, (iii) the benefits of considering the wider needs of young people as they transition from childhood to adulthood, (iv) the value of having a co-ordinated and multi-agency approach to transition and (v) an emphasis on

providing skills-training for young people, families and staff and measurable outcomes. These themes will be covered in more detail next.

Timing

Current evidence has suggested that transition should begin early and be delivered in a timely and co-ordinated manner (American Academy of Paediatrics and Medicine. 2002, Department of Health 2004, Department of Health 2010c). In the UK, the Department of Health (2010) highlighted that:

Successful transition depends on early and effective planning, putting the young person at the centre of the process to help them prepare for transfer to adult services. The process of transition should start while the child is still in contact with children's services and may, subject to the needs of the young person, continue for a number of years after the transfer to adult services. This will ensure that young people and parents know about the opportunities and choices available and the range of support they may need to access.
(Department of Health 2010c, para. 138)

While the exact timing of transition from children's to adolescent or adult services varies from person to person and is, to a certain extent dependent on which adult services are available, it is generally accepted that the majority of young people move from children's to adult services when they are aged between 16 and 18 years. It is important that transition is not viewed as a single event but as a process that gives the young person and their families plenty of time to prepare for the move from child to adult services. This was emphasised in the recent cross Governmental Mental Health Strategy, "No health without mental health", which reported that "careful planning will prevent arbitrary discontinuities in care" that are likely to be distressing for the young person and their families (Department of Health 2011a). Arbitrary transfers and healthcare discontinuities also increase the likelihood of young people disengaging with health services and could therefore have severe consequences on their health and wellbeing. NICE (2008) similarly highlighted that transition should be planned in advanced by both the referring and receiving services and that an assessment at school-leaving age to establish the need for continuing treatment into adulthood should be carried out (National Institute for Clinical Excellence 2008).

The importance of continuity of care was also highlighted by Sir Ian Kennedy who in 2010 published his review of Children's Health Services in the UK. In his review, he stressed how abrupt transfers are currently failing to meet the needs of young people and argued that these should be brought to the forefront of healthcare provision and replace current "bureaucratic barriers" between paediatric and adult care:

Arrangements must be agreed, regarding funding and other matters, to address the changing needs of children and young people as they mature, including greater continuity of care into adulthood. Ensuring a smooth transition between children's and adults' services should be a priority for local commissioners (Kennedy 2010, Recommendation 32).

To ensure that transition takes place at the appropriate time for the individual rather than at a specific time point, flexibility in the way that services are provided is required (Department for Education and Skills 2007, Department of Health 2004, Department of Health 2008). Indeed, flexibility dependent on young people's development was emphasised by the NSF which delineated several standards for mental health services that have remained part of the Governments overall policy objectives. These emphasized, for example, access to age-appropriate and flexible services which are responsive to specific needs of all young people as they attain adulthood, highlighting that "all young people are to have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood" (Department of Health 2004).

Informing and involving the young person and family in the transition process

In addition to the emphasis that transition should take place at the appropriate time, another key theme in the transitions literature relates to young person and their family being informed and involved in the transition process. Policy documents have called for young people and their families to be in control of the design and delivery of their care package and be supported to shape services (Department for Education and Skills 2007, Department of Health 2006, Department of Health 2011c, Doug et al. 2011). Young people and families should be able to input into the transition planning (Department for Education and Skills 2007, Rosen et al. 2003, Royal College of Physicians of Edinburgh 2008); requiring that they are provided with accurate and easy to understand information about local services and the transition process (Department for Education and Skills 2007, Department of Health 2011c,

National Institute for Clinical Excellence 2008), for example, information regarding how child and adult health services tend to be organised in very different ways and have different cultures.

Importantly, the young person should have a transition review that includes a needs assessment and leads to a comprehensive health transition plan developed with the family (Department of Health 2008, Royal College of Nursing 2004). The UK good practice guidance “Transition: moving on well”, for example, highlights that a health transition plan prepared by healthcare professionals should include an action plan to meet the needs identified by the young person, in preparation for moving into adult healthcare (Department of Health 2008). Other guidelines have stressed that the development of the transition plan should be a continuous process that includes checklists for key areas (American Academy of Paediatrics and Medicine. 2002, Department of Health 2008, Royal College of Nursing 2004) and a statutory year 9 review for young people with special educational needs, learning difficulties and disabilities (Department for Education and Skills 2007).

It is important to note that the 2011 SEN and Disability Green Paper “Support and aspiration: A new approach to special educational needs and disability” (Department of health 2011b) proposed that by 2014 there should be a single assessment process for those with special educational needs that consists of a “Education, Health and Care Plan” which will give support from birth to the age of 25 years. This would replace the two different systems currently in place (the under-16s SEN statement system and the over-16s learning difficulty system) with one consistent system. It is hoped that this will give families confidence that all of the different local agencies – across education, health and social care will be working together to meet their needs. It is also expected that this will stop parents from having to undergo repeated assessments with different agencies and end the dramatic “cliff edge” young people face when they leave school at 16 or 18, losing statutory rights when SEN statements stop and triggering a completely new reassessment which carries far less protection (Department of health 2011b).

The proposal of the SEN and disability green paper followed existing good practice and the previous activity of the Aiming High for Disabled Children (AHDC) programme, an investment and transformation programme run jointly by the Department for Children, Schools and Families and the Department of Health for services for disabled children and

their families in England between 2008 and 2011. As a result of the AHDC programme, a Transition Support Programme (TSP) was created to support service improvements to promote disabled young people's transition to adulthood between March 2011 and November 2011. Since then, a new government programme called “The Preparing for Adulthood programme” has been providing knowledge and support to all local authorities and their partners, including families and young people, to ensure young people with SEN and disabilities achieve paid work, independent living, good health and community inclusion as they move into adulthood (www.preparingforadulthood.org.uk).

Person-centered approach which attends to a wide range of needs

In addition to the themes of providing timely transitions that involve and inform young people and their families of the transition process, the idea that transitional care should be person-centred and needs-focused, thereby placing the young person at the centre of transition-planning is also a key policy theme (Department of Health 2004, Department of Health 2008, Department for Education and Skills 2007, Kennedy 2010, Rosen et al. 2003, Department of Health 2011c). Both child and adult teams should provide a service that is young person friendly. This is defined by the Department of Health in the You're Welcome quality criteria which include opportunities for young people to be seen alone, clinics with other young people and the use of methods of communication preferred by young people (Department of Health 2011c).

In addition, several surveys of young people with various chronic conditions and their care givers have shown the benefits of attending to the wider needs of those at transition from child to adult services (Lotstein 2005, While et al. 2004). Indeed, helping young people with broader life issues such as education, employment and housing has been shown to lead to improvements in their mental health, maybe because this leads to a closer engagement with the young person which is necessary to determine their needs as they move from child to adult services (Department of Health 2008).

Coherent and multidisciplinary approach

Given the emphasis on considering the wider needs of young people as they make the move from child to adult services, transitional healthcare is increasingly viewed as a process that requires a coherent and multidisciplinary approach. The need for greater integration between

services is emphasized in the new Health and Social Care Act of 2012. The act highlights the need for clinicians and services to work together to improve the health and wellbeing of their local population and reduce health inequalities. It is intended that by April 2013 each top tier and unitary authority will have its own health and wellbeing board. Board members will collaborate to understand their local community's needs, agree priorities and encourage commissioners to work in a more joined up way. As a result, patients and the public should experience more joined up services from the NHS and local councils in the future.

Similarly, in The White Paper, "Healthy Lives, Healthy People; Our Strategy for Public Health", published in November 2010 (Department of Health 2010b) the government highlighted its continuing commitment to developing a coherent approach to key transitions, instead of tackling issues in isolation. Consistent multi-agency working is seen as a way to ensure that young people are given a real choice about their future as well as ensuring effective information sharing between services and professionals (American Academy of Paediatrics and Medicine. 2002, Department of Health 2004 Department of Health 2008 Department for Education and Skills 2007 (National Institute for Clinical Excellence 2008, Royal College of Physicians of Edinburgh 2008).

Integration of care is particularly important for young people at transition from child to adult health services as this process commonly occurs alongside other huge changes that accompany young people's transition to adulthood. These include physical, emotional and legal changes and important changes in roles, relationships, expectations and status (Townesley 2004). For example, many young people have to manage transitions within education whether that involves moving into a school sixth form or from school to further education or training. Moreover, they may be leaving education and going out to work, leaving home to move into their own accommodation, or moving on to adult social services provision. All of these changes require that health professionals work creatively and flexibly to help contribute to the development of the long term plans for education, employment and social support considering the nature of the young person's condition and disability. For example, they may need to provide information and interpretation on the natural history of the disorder and the likelihood of improvement or deterioration, the treatment options, and the risks of various courses of action.

However, while a multi-agency approach to transition may be the most beneficial, it is recommended that every young person should have an allocated member of staff who is responsible for organising their transition (Department of Health 2008). This person will also be responsible for ensuring that the young person is supported throughout the process and receive all the preparation needed to feel ready to move to adult services. Usually clinical nurse specialists or consultants take the ‘transition coordinator’ role although other members of staff may be involved in the process. In addition, Connexions, the advice and guidance service for young people aged 13 to 19, is available to young people with learning difficulties and disabilities up to the age of 25. It provides support to all young people with additional needs during their transitions to adulthood and can act as the lead in promoting this multi-agency approach (Department of Health 2008).

Skills-training and measurable outcomes

As young people in adult services are generally expected to take increasing responsibility over their own health, several guidelines have addressed the need to ensure that these young people have all the skills necessary to feel comfortable in adult health services. For example, it has been recommended that transition should develop the young person’s knowledge, confidence, self-advocacy and self-management skills (Department of Health 2006, Department of Health 2008). In addition, staff should also be trained in working with young people and transition issues (Department of Health 2006, Department of Health 2008, Kennedy 2010, Rosen et al. 2003). This is reflected, for example, in the quality criteria set out by the Department of Health in “Quality criteria for young people friendly health services”, also referred to as “You’re welcome”, in May 2011 which is intended to encourage staff to have special training and clear procedures to prepare young people, and their parents or carers, for transition from the age of 12 onwards and to develop services that are more youth friendly (Department of Health 2011c).

Although important components of effective transition services have been identified, there is currently little evidence about the best ways to develop and then evaluate effective transitional care in healthcare provision (Bowen et al. 2010, McDonagh and Kelly 2010, While et al. 2004). Hence, there is currently no prescribed “best practice” model to meet the needs of young people in transition. The good practice guidance, “Working at the CAMHS/Adult Interface” describes a range of models which have been developed to support

young people and young adults as they move from child to adult services (Lamb et al. 2008). It specifically recommends three types of service models, which could be delivered alone or in combination: (i) a designated stand-alone transition services, (ii) a designated transitions team within an existing AMHS or CAMHS service, and (iii) designated staff trained in working with young people seconded to AMHS teams (Lamb et al. 2008).

Due to the lack of one prescribed best practice model, a range of guidelines have emphasised the need for services to be regularly reviewed and audited to ensure a value for money service (Department of Health 2011c, Royal College of Nursing 2004, Royal College of Physicians of Edinburgh 2008). For example, the government recently recommended that for young people in contact with mental health services, a number of assessment processes, planning systems and quality criteria can be used to audit and evaluate service performance and staff practices including the CAF (Common Assessment Framework) and the Framework for the Assessment of Children in Need and their Families; the CPA (Comprehensive Performance Assessment); in addition to the “You're welcome” quality criteria for young people friendly health services mentioned earlier (Department of Health 2011c).

3.5 Guidelines relating to adults with ADHD

As mentioned at the beginning of this chapter, guidelines relating to the diagnosis and management of ADHD across a lifespan are few in number (Canadian Attention Deficit Disorder Resource Alliance 2011, National Institute for Clinical Excellence 2008); however, two additional guidelines focus specifically on adolescents and adults (Nutt et al. 2007) and adults (Kooij et al. 2010). The focus on adolescents and adults follows increasing evidence showing the high prevalence of ADHD among adults who suffer from ADHD symptoms and impairments in adulthood.

3.5.1 Diagnosis of adults with ADHD

As in the diagnosis of children with ADHD, a diagnosis (or re-assessment) of ADHD in adults should only be made by a specialist psychiatrist, or other appropriately qualified healthcare professional with training and expertise in the diagnosis of ADHD. This should be made on the basis of a full clinical and psychosocial assessment of the person which should include discussion about behaviour and symptoms in the different domains and settings of the person's everyday life, a full developmental and psychiatric history, and observer reports and

assessments of the person's mental state. School reports may be helpful and necessary to establish that ADHD was present in childhood, as can informant reports. In addition, rating scales developed for adults, such as the Conners' rating scales, are recommended as valuable adjuncts to establish the presence of ADHD in adulthood, and observations are useful when there is doubt about symptoms (National Institute for Clinical Excellence 2008).

An important aspect of diagnosing ADHD in adults is to identify other psychiatric/developmental conditions (including mood disorders, anxiety disorders, addiction problems, pervasive developmental disorders, specific learning disabilities and personality disorders) that may co-exist (comorbidities) or mimic (differential diagnosis) ADHD symptoms. Neuropsychological correlates of ADHD have been extensively investigated and neuropsychological testing is often used in the clinical situation. However, controversy exists as to the choice of tests and the diagnostic significance of test findings. Careful physical and psychiatric examination including baseline vital signs, blood tests and electrocardiography, is needed to exclude ADHD features being secondary to a physical disease but also for the purposes of monitoring side-effects of pharmacotherapy.

The fixed symptom threshold in the DSM-IV is unfortunately only based on children (aged 4 to 17 years); however, the diagnostic criteria are used for all ages. Many items are not entirely applicable to adults. For example, behaviours such as "often has difficulty playing or engaging in leisure activities quietly"; "often runs about or climbs excessively", or "often avoids or strongly dislikes tasks that require sustained mental effort". Thus, fewer items can be used to rate adults, and fewer chances to meet criteria result.

Moreover, because ADHD is conceptualised as a developmental disability, target symptoms must be age-inappropriate relative to peers. These sorts of considerations highlight that current DSM-IV standards are less appropriate for adult sufferers, who may still have relative deficits and show many ADHD-based problems but do not fully meet criteria (Barkley 2002). That is, they may have "outgrown" the normative sample, but not the disorder. Accurate diagnosis of adult ADHD therefore remains a clinical challenge as it is a disorder representing extremes of normal behaviours, with no clear consensus regarding the clinical boundaries (Levy et al. 1997).

3.5.2 Management of adults with ADHD

Clinical guidelines for managing adults with ADHD are unanimous in their recommendation that treatment for adults with ADHD needs to be multimodal and the adults with ADHD require support and follow-up over time. For example, the Canadian guidelines for adults with ADHD recommend that ongoing education regarding strategies for coping, in addition to medication, is necessary to allow the patient to obtain developmental and functional gains that would not otherwise be possible (Canadian Attention Deficit Disorder Resource Alliance 2011). A detailed summary of the key recommendations given in the NICE (2008) guidelines can be found in Appendices M-N.

Drug treatment

While the NICE guidelines recommend that drug treatment for children and young people should be reserved for severe cases, NICE recommendations for adults state that drug treatment should be started first (with methylphenidate as the first line treatment) unless the person prefers a psychological approach. Similar to children and young people with the disorder, drug treatment in adults with ADHD should only be started by an appropriately qualified healthcare professional with expertise in ADHD and should be based on a comprehensive assessment and diagnosis. In addition, drug treatment should always form part of a comprehensive treatment programme, which should aim to meet psychological, behavioural, and educational and/or occupational needs (National Institute for Clinical Excellence 2008). This emphasis on the importance of providing a comprehensive treatment programme can also be found in the Canadian ADHD guidelines (Canadian Attention Deficit Disorder Resource Alliance 2011) which recommend that true optimal treatment must include lifestyle changes which may involve psychoeducation, behavioural interventions and assistive technologies such as various hardware and software to diminish a patient's reliance on working memory and to compensate for poor handwriting as well as improve time management (Canadian Attention Deficit Disorder Resource Alliance 2011).

Regarding the duration, discontinuation and continuity of treatment, NICE recommends that drug treatment for adults should be continued for as long as it is clinically effective (please see Appendix N). An annual review should be carried out including a comprehensive assessment of clinical need, benefits and side effects, taking into account the views of the

person and those of a spouse, partner, parent, close friends or carers wherever possible, and how these accounts may differ (National Institute for Clinical Excellence 2008).

Psychological treatments

As with children and young people with ADHD, NICE (2008) recognises the need to provide an inclusive comprehensive treatment programme for adults with ADHD while acknowledging that medication treatments are unlikely to address all of the domains of impairment associated with ADHD (especially comorbid disorders such as anxiety, depression, and learning disabilities). NICE (2008) also recommends that for those in whom symptoms are remitting, psychological treatments may be sufficient to target residual functional impairments. Otherwise, psychological therapies should be offered to those adults stabilised on medication who still have persisting functional impairment associated with the disorder and to those who have had no response to drug treatment (or who prefer not to take medication). Such therapies include either group or individual CBT to address the person's functional impairment. Group therapy is recommended as the first-line psychological treatment due to its cost-effectiveness (National Institute for Clinical Excellence 2008).

In contrast to the weak evidence base for CBT in children with ADHD, the role of CBT for the treatment of ADHD in adulthood is growing. Indeed, a number of studies have shown that cognitive behaviour therapy for adults with ADHD can be effective with or without medication. For example, Safren and colleagues (2005; 2011), developed a group-delivered cognitive behavioural therapy programme for adults with ADHD as a supplement to their medication treatment. Results of this manualized therapy have been favourable in showing significant benefits beyond those achieved by medication alone (Safren et al. 2005). A year later, Rostain and Ramsey (2006) similarly reported that the combination of medication and CBT treatment (the latter adapted specifically for adults with ADHD) was more beneficial than medication alone. Seventy per cent of the participants in the combination treatment group showed moderate to significant improvements in ADHD symptoms in addition to improvements in depression, anxiety and hopelessness scores (Rostain and Ramsay 2006). More recently, Solanto and colleagues reported on the efficacy of a 12-week metacognitive behavioural therapy intervention that focused mainly on time management and organizational skills in adults with ADHD (Solanto et al. 2010) whereas in Iceland, Emilsson and colleagues reported the efficacy on a newly developed cognitive behaviour therapy (CBT) based group

programme, the Reasoning and Rehabilitation for ADHD Youths and Adults (R&R2ADHD). This latter programme showed promising results in reducing ADHD symptoms and comorbid problems, and improving functions associated with impairment (Emilsson et al. 2011). These, and other similar findings, suggest that psychopharmacological and CBT based treatments may add to and improve pharmacological interventions.

In summary, several guidelines, including those by NICE (2008) have been published on the management and care of children, young people and adults with ADHD that should make people with ADHD, and their families more confident that their problems will be recognised and helped. These guidelines should also provide professionals with a framework for good practice nationally. While clearly stating what the most effective treatments are, the guidelines are also explicit in ensuring that people's choices for different treatment options can be taken into account if they find one treatment more acceptable than another, or if their first choice of treatment proves to be unsuitable.

3.6 Management and care of people with ADHD: What happens in practice? A review of the literature

Although clinical guidelines have provided recommendations for diagnosing, assessing and treating ADHD, guidelines do not necessarily change clinicians' behaviour (Cabana et al. 1999). Recent studies looking at clinicians' experiences and attitudes to assessing, diagnosing and treating ADHD, have suggested that clinicians working with people with ADHD may find making decisions about ADHD challenging (Kovshoff et al. 2012). Kovshoff and colleagues (2012) found that the reasons for this included: (i) the absence of a medical or biological test which would confirm or disprove the existence of ADHD, (ii) reliance on information collected from caregivers, teachers and the child and the inherent subjectivity of these reports, (iii) the need to integrate different and perhaps contradictory perspectives; and (iv) the lack of clear and universally accepted and operationalized clinical practice guidelines (Kovshoff et al. 2012). A previous review of studies examining barriers to following clinical guidelines found that the most common barriers included: (i) lack of awareness and familiarity with the guidelines, (ii) disagreement with the guidelines, and (iii) external factors which are patient related (e.g. patient preference or the patient not agreeing with the recommended guideline or treatment) or environmental factors (e.g. lack of resources or facilities) (Cabana et al. 1999).

3.6.1 Management of children with ADHD in practice

A review of literature into the provision of treatments and interventions for children and adolescents with ADHD shows that provision of care for people with ADHD is highly variable (National Institute for Clinical Excellence, 2008). Although primary care, mental health and educational systems all play essential roles in caring for youth with ADHD, research evidence highlights that much work needs to be done to translate the recommendations set out in the guidelines into practice (Leslie and Wolraich 2007). For example, NICE (2008) reviewed assessment approaches in ADHD and concluded that there is a lack of consistent assessment and treatment protocols for ADHD in the UK (National Institute for Clinical Excellence 2008). The review showed that children who require assessment for ADHD are usually seen by primary services and then referred to more specialist services for full assessment or treatment. Referrals into health services are made to a range of healthcare providers, including primary mental health workers, nurses, child psychiatrists, psychologists, and general or specialist paediatricians depending on local protocols and services (National Institute for Clinical Excellence 2008).

Under-treatment

Another consistent finding has been the lack of specialist healthcare use by young people with ADHD. For example, Sayal and colleagues (2006) using nationally representative data from the 1999 British Child and Adolescent Mental Health Survey, examined rates and correlates of parental recognition of childhood mental health problems (and contact with services for these problems). They reported that only one third of children with ADHD had received specialist services and hence had been in a position to access evidence based treatment, indicating a large under-treatment and unmet need at a population level (Sayal et al. 2006). Other studies on treatment utilisation have similarly suggested that only half of children with ADHD receive treatment, and less than half of them receive specialty care (Canino et al. 2004, Jensen et al. 1999). Fewer children receive psychostimulant medication than would be expected with estimated prevalence rates, which supports the claim that ADHD is under-diagnosed and under-treated (National Institute for Clinical Excellence 2008).

Lack of comprehensive care

There is also general agreement that CAMHS are generally patchy and that there are challenges in providing comprehensive care for all young people with mental health problems (Davren 2007). Diagnosis and treatment of mental health problems in the UK largely occurs within primary care services, with fewer than one in ten patients being referred to specialist psychiatric care, in line with the model of care recommended by the NSF (Goldberg and Huxley 1992). Although being diagnosed with a psychiatric disorder does seem to be related to service use, there is evidence that certain psychiatric disorders are more recognised and more likely to receive treatment, with some studies suggesting that children with disruptive or externalising symptoms are more likely to be seen than those with emotional or internalising disorders (Anderson et al. 1987, Garralda and Bailey 1988, Sourander et al. 2001).

GPs fail to recognise ADHD

Primary care may be partly to blame for the lack of specialist care received by people with ADHD. A recent survey carried out by The National Attention Deficit Disorder Information and Support Services (ADDISS) of 50 child and adolescent psychiatrists and 75 paediatricians in the UK found that General Practitioners (GPs) often fail to recognise cases of ADHD (ADDISS 2003). The knowledge of GPs in the area of ADHD and related developmental disorders may be inadequate and sometimes less developed than that of teachers (ADDISS 2003). Moreover, GPs may be reluctant to manage people with ADHD due to misperception that initiation (and ongoing monitoring) of pharmacological management of ADHD should be the responsibility of a specialist (Ball 2001). This is despite recent recommendations in national and European clinical guidelines for hyper-kinetic disorder which state that once a child is stabilized on medication for ADHD, they can then be followed-up in primary care (National Institute for Clinical Excellence 2008, Taylor et al. 2004).

It has been shown that GPs are more likely to be more influenced by their clinical experience than research evidence when it comes to making changes to their practice (Mayer and Piterman, 1999). If there was a conflict between local practice and the research evidence, Mayer and Piterman (1999) found that GPs would discuss the matter with local colleagues and local specialists rather than critically appraise the evidence base (Mayer and Piterman 1999). More specifically, GPs' views about ADHD have been found to be old-fashioned and

in discordance with the evidence base (Klasen and Goodman 2000). Klasen and Goodman (2000), who compared parents and GPs' views about ADHD in a qualitative study found that GPs were uncertain whether to view hyperactivity as a medical disorder, often regarding it as a passing phase related to family stress. GPs acknowledged that the decision to refer was often based on parental request or difficulties in managing the behaviour rather than on the severity of the problem (Klasen and Goodman 2000).

Perceived parental burden

Barriers to treatment may also exist earlier in the help seeking pathway and may not simply be due to problems at the primary care level. Sayal et al (2006) found that although most (80%) of the parents of children with ADHD recognised that their child had a problem many did not consult primary care for these problems (Sayal et al. 2006). Research has suggested that parents may be concerned that they could be blamed for their child's problems (Klasen and Goodman 2000). Sayal and colleagues (2006) found that the impact of the young person's ADHD symptoms on family members best predicted parental recognition of problems and help seeking behaviour (Sayal et al. 2006).

Health service use

A recent survey of the range and availability of ADHD treatment services in the UK found that lack of staffing, and staff training specifically in ADHD (along with long waiting lists and lack of multidisciplinary approach) is common (Tettenborn et al. 2008). This study found that only one paediatric centre included in the study reported that collaboration with CAMHS was a regular component of diagnosis and follow-up, despite the endorsement of a collaborative approach at a government level reflected with the publication of the NSF (Department of Health 2004). The authors of the survey highlighted the need for current services to improve if the markers of good practice set out by the NSF are to be met (e.g. fast access to mental health assessment, appropriate skill mix and training of care teams) (Tettenborn et al. 2008).

Studies have also indicated that in general, regardless of the morbidity burden, individuals in the UK are less likely to have specialist referrals than those in the US. Forrest and colleagues (2002) compared speciality referral rates between the UK and the US among children and young people and found that 30 to 36% of patients per year were referred in the US compared

with 14% per year in the UK. US patients were referred more commonly than UK patients, regardless of the type of complaint or burden (Forrest et al. 2002). The generally low availability of specialists and resultant long waiting lists in the UK may explain some of these differences.

Medication

Currently, management of ADHD in children and adolescents in the UK mostly involves the use of stimulant medication. The use of stimulants in particular to treat ADHD has increased dramatically since the last decade despite controversy about their effectiveness and potential adverse effects. Drug treatment for ADHD in children in the UK was very rare until the mid-1990s but it is now the main form of treatment for children with this disorder. Ford and colleagues (2008) followed a clinic-based cohort of young people aged 12 years and over with ADHD (n=115) five to seven years after diagnosis and found that nearly all the young people (93%) had taken medication at some point, particularly methylphenidate (91%), while a few young people had taken dexamfetamine (6%), atomoxetine (4%), antipsychotics (3%) or clonidine (1%). The mean age of starting medication reported by parents was 8 years old (sd 1.9). At the time of reassessment, when most were aged 14, Ford and colleagues found that 66% of this clinic-based cohort of young people were still taking medication. Nearly two thirds were taking some sort of stimulant, 37% modified released methylphenidate, 26% immediate release methylphenidate, and 3% dexamfetamine. A few young people were taking non stimulant drugs, 2% antipsychotics, 1% clonidine, and 1% atomoxetine. General practitioners were prescribing with the support of specialists for most (82%) of the young people taking medication at follow up (Ford et al. 2008).

Hsia and MacLennan (2009) also compared the rise of stimulant medication in several general practices among children and adolescents aged less than 19 years of age in the UK between 1992 and 2001 to the use of other psychotropic medications. The authors found a significant rise in the prescription of stimulant medication alongside increases in the prescription of antidepressants (aged 13 to 15), hypnotics/anxiolytics (aged 13 to 15), antipsychotics (aged 10 to 18), and anticonvulsants (aged 6 to 18) among children and adolescents (aged 3 to 18) during this period (Hsia and MacLennan 2009).

However, attitudes and practices to treatment with stimulants can vary greatly among practitioners. In Scotland, for example, prescription rates for stimulants for people with

ADHD vary sevenfold across health boards. Although variability in the quality of diagnosis of ADHD is likely to result in some inappropriate prescription of stimulants, most of the evidence suggests under-recognition and under-treatment (Coghill 2004). NICE, using a conservative approach to decision making in treatment, reported that in England and Wales only 30% of patients with hyperkinetic disorder, the most severe form of ADHD, were receiving stimulants (National Institute for Clinical Excellence 2008). Evidence suggests a similar situation across the rest of the United Kingdom.

Lack of psychosocial interventions

There is a lack of availability of psychosocial approaches or the ability to assess or manage coexisting conditions (National Institute for Clinical Excellence 2008). Indeed, several studies have suggested that the multi-modal and multidisciplinary management of people who have been diagnosed with ADHD as recommended in the guidelines is not occurring. For example, an audit carried out by Moosa & Lohawala (2007) of an inner city CAMHS in Birmingham showed that although the service scored well in areas of assessment and management with stimulants it failed to adhere to guidelines in terms of providing psychosocial interventions in addition to medication (Moosa and Lohawala 2007). A survey carried out by Skilling and colleagues (2007) of ADHD follow-up services provided by children and adolescent psychiatry departments across Scotland found that less than half of these departments had designated multidisciplinary ADHD follow-up teams as recommended by the Health and Social Care Advisory Service report (HASCAS 2004). The majority of these follow-up teams were provided solely by medical staff, usually consultant psychiatrists, who were less likely than multidisciplinary teams to provide detailed medical, educational and social assessments required for ongoing monitoring as well psychosocial interventions (Skilling et al. 2008).

Variations in the services and supports provided for people with ADHD reflect different views of what interventions work and for whom. On the one hand studies have found that combined treatment approaches that utilize both behavioural treatment and medication are effective in reducing ADHD symptoms and additional comorbidities (Frame 2003, Kazdin 1997, Kendall and Shelton 2003). On the other hand, studies have disagreed that a combined approach is any more effective than medication alone (Jensen et al. 2001, The MTA Cooperative Group 1999, Pelham et al. 2001, Wilmott and Laustsen 2003). The lack of

consensus on the most appropriate modes of treatment within the healthcare profession regarding the management of ADHD is likely to impact on the care that young people receive.

Therefore, it appears that despite the plethora of policy documents and initiatives, there are still variations in service provision for young people with mental health problems, both between regions and within the local areas in the UK, leading to inequalities in care provision (National CAMHS Review 2008).

3.7 Healthcare transition from child to adult services in practice

There is widespread recognition that the transition from child to adult health services can be problematic, with poorly defined procedures and a lack of coordinated care planning (Davis 2003, Department of Health 2006, Department of Health 2010a, Kennedy 2010, Singh et al. 2010b, Vostanis 2005). In his review of young people's services in the UK, Sir Kennedy identified the problem of healthcare transition as a critical area for policy (Kennedy 2010). He noted that shortcomings in care arising from healthcare transition add weight to a wider feeling that young people (and adolescents in particular), are a "forgotten group" caught between child and adult health services (Kennedy 2010). This corresponds to the finding that young people themselves appear dissatisfied with transition arrangements (DARE Foundation 2006). In a study by the National Advisory Council (NAC) it was found that what young people want most of all in terms of transition is: (i) to be listened to and understood, (ii) to be taken seriously, (iii) to experience well planned, smooth transitions, (iv) to receive flexible services, (v) to have information and choice and (vi) to have continuity of care (National Advisory Council Young People's Reference Group 2009).

Few studies have investigated the process or outcomes of healthcare transition in the UK among young people with mental health problems (Singh et al. 2010b). In fact, most studies on healthcare transition are from a non-UK perspective or address chronic illness, physical disability and learning disability, e.g. physical disability (Ko and McEnery 2004, Sloper et al. 2010); HIV (Miles et al. 2004); brain injury (Kent and Chamberlain 2004); cerebral palsy (Donkervoort et al. 2009), cystic fibrosis (Cowlard 2003, Craig et al. 2007); diabetes (Allen and Gregory 2009, Bowen et al. 2010, Cadario et al. 2009, Holmes-Walker et al. 2007, Nakhla et al. 2009) learning disability (Cameron and Murphy 2002), liver transplant

recipients (Fredericks et al. 2010), renal (Watson et al. 2010). In their recent systematic review of the evidence for the effectiveness of transitional care interventions in improving health outcomes in a broad range of conditions, Crowley and colleagues highlighted the paucity of high quality research in this area (Crowley et al. 2011), a finding that is in line with earlier international reviews (While et al. 2004).

Most of what is known about the transfers and processes of healthcare transition in young people with ADHD comes from a study by Singh and colleagues who in the UK examined the process, outcomes and experience of transition from CAMHS to AMHS (Singh et al. 2010b). The TRACK study (Transitions of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services) found that optimal transition (defined as adequate transition planning, good information transfer across teams, joint working between teams and continuity of care following transition) was experienced by less than 5% of those who made a transition and that those with a history of severe mental illness, those who were on medication, or those who had been admitted to psychiatric hospital were more likely to make the transfer than those with neurodevelopmental disorders, emotional/neurotic disorders or emerging personality disorder (Singh et al. 2010b). Singh and colleagues (2010) concluded that their findings suggest that the complexity of service structures, arbitrary service boundaries, variation in protocols and possible policy-practice gap all contribute to discontinuities in mental health care for a significant number of young people who experience no or poor transition of care across services (Singh et al. 2010b).

Timing

Despite the NSF's emphasis on flexibility in regards to when young people make the transition to adult care (Department of Health 2004), studies have consistently found that many young people experience transition as a disruptive processes involving a sudden move from child services (Kennedy 2010). Sir Kennedy argued that the current "problem of transition" stems from the administrative divisions between different NHS services whereby transitional care is viewed from the perspective of organisations providing services, rather than the children and young people being cared for. While a young person's needs and the care that they require to meet them evolve, services arrangements in the UK currently lead to abrupt changes in services when young people reach an arbitrary point (usually their 16th or 18th birthday) (Kennedy 2010).

Singh and colleagues (2010b) similarly, in discussing findings from their TRACK study, reported that the young people and families identify informal and gradual preparation for transfer as key to having a positive experience of transition. Singh and colleagues noted that the majority of protocols they examined did mention the need for flexibility when applying age-based transition criteria, however there seemed little consensus either on how such flexibility can be mutually agreed between services or operationalised in protocols (Singh et al. 2010b).

Rigid age demarcations were also highlighted in the recent guidance report entitled “Mental health service transitions” by the Social Care Institute for Excellence (Social Care Institute for Excellence 2011) which confirmed that discharge from CAMHS and a potential move to AMHS currently occurs most commonly when young people are aged between 16 and 18. Any flexibility to this rule appears to apply only if a person has a learning disability or is “looked-after” who often continue to receive services until the age of 21 or 25 if they remain in education (Social Care Institute for Excellence 2011). Such rigid age demarcations between services have been criticised widely for leading care providers to ignore the developmental needs of individuals (Kennedy 2010, Lamb et al. 2008, McGorry 2007). This may help to explain the several concerns that service users and carers have about transition to AMHS identified in the TRACK study, including fear of the unknown, reluctance to move from CAMHS and a feelings of ‘loss’, uncertainty about what AMHS offered and feeling intimidated at the first CPA meeting (Singh et al. 2010b).

In discussing the separation of child and adult mental health systems, McGorry (2007) proposed a youth mental health model arguing that:

public mental health services have followed a paediatric-adult split in service delivery, mirroring general and acute healthcare. The pattern of peak onset and the burden of mental disorders in young people mean that the maximum weakness and discontinuity in the system occurs just when it should be at its strongest (McGorry 2007, p. 53).

This child and adult split and the lack of sufficient and developmentally appropriate services and supports are likely to severely hamper these individuals’ ability to become functional adults. While young people at transition from child to adult health services face the same challenges that all young people face during this transition period, they also carry the added

burden of a largely invisible disability and no unified public agency is designated to them move into adulthood (Wagner et al. 2005). Consequently, transition-age youth with emotional and behavioural difficulties experience poorer long-term outcomes than do their peers. These may include school dropout, unemployment, contacts with juvenile or criminal justice system, substance misuse disorders, early and unplanned pregnancies, and homelessness. The transition to adulthood for young people with developmental disorders is therefore complex, extremely problematic, and in many cases, highly unsatisfactory (Beresford 2004, p. 582).

There is some evidence that great improvements can be made to healthcare transition if transition planning starts early and when the young person's readiness for transition is assessed prior to initiating transitioning. Methods of assessing readiness for transition have gained more attention recently (Fredericks et al. 2010, Sawicki et al. 2011, van Staa et al. 2011, Williams et al. 2010). Sawicki and colleagues have published preliminary validation data of the Transition Readiness Assessment Questionnaire, which appears to be useful both to assess transition readiness and to guide educational interventions by providers to support transition (Sawicki et al. 2011). Tools are also being designed for specific conditions, for example, the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence (Donkervoort et al. 2009).

Informing and involving the young person and family in the transition process

While service user and parent/carer involvement in transition planning is ubiquitous as a principle in transition policies, few policies specify ways of preparing young people and families for transition (Singh et al. 2010b). There is evidence that young people may have little understanding of, or expectation about, what transition means, and many lack the information they need (Yu 2008). Parents and carers have said that young people's voices are not heard, and therefore they have to advocate on their behalf (Davis 2003, Mills and Francis 2010, Yu 2008). Indeed, in their review of the literature, Munoz-Solomando et al (2010) reported that there is little literature available that documents the personal experiences of young people in transition and their families, but from what is available, the literature suggest that involving young people directly in planning their own care is pivotal in improving healthcare transition (Munoz-Solomando et al. 2010).

Indeed, studies examining young people's involvement in the transition process have provided strong evidence to suggest that many young people, particularly those who are

disabled, are not properly involved in the decision-making (Heslop et al. 2002, Singh et al. 2010b, Ward et al. 2003). For example, Heslop and colleagues' (2002) survey of over 250 families found that four out of 10 young people with a disability had little, if any, involvement in the transition planning process with a quarter having no involvement (Heslop et al. 2002). Similarly, Singh and colleagues (2010) noted that based on their findings from the TRACK study, transition protocols need to give specific guidance as to how young people and families should be prepared for transition. In addition, a major omission from protocols was procedures to ensure continuity of care for patients not accepted by AMHS (Singh et al. 2010b).

Person-centred approach which attends to a wide range of needs

Although government documents have advocated the importance of providing person-centred and young person friendly services for young people at transition (Department of Health 2007, Department of Health 2011c), a number of studies have highlighted that much more needs to be done to achieve this in practice. For example, studies point to few young people being offered healthcare appointment independently of their carers (Mappa et al. 2010, Suris et al. 2009), an important aspect of a young friendly services as defined in the You're Welcome quality criteria by the Department of Health (Department of Health 2007). Mappa and colleagues, for example, reported that their survey in a UK hospital revealed that only 23% of clinicians routinely asked young people if they wanted to be seen independently of their carers. Worryingly, 43% thought it was not essential and 30% were concerned about the extra time that may be required (Mappa et al. 2010).

Similarly, Singh and colleagues reported that although several policy documents have stressed the need to involve service users and carers in the transition process and decision making and prepare them for transition none of the protocols included in the TRACK study specified ways of preparing service users or carers for transition. Furthermore, the study showed that users and carers felt that AMHS care was focused on medication and that psychiatrists dealt with medication but not emotional and social issues. For many young people transition was a complex and unsettling experience including moving out of parental home, relationship problems, being homeless or in supported accommodation, being pregnant or becoming physically unwell. These other life transitions, including changes in housing, pregnancy, physical illness, and the involvement of parents or other services were sometimes

powerful extraneous influences on transition experiences (Hovish et al. 2012). The authors concluded that the cumulative effect of multiple transitions is a complex and unsettling experience for many service users. Service users experience of healthcare transition is more likely to be positive if healthcare transition is a gradual process, tailored to the individual's needs and managed in the context of other simultaneous, practical, developmental and psychosocial transitions (Hovish et al. 2012, Singh et al. 2010b).

This complexity was also noted prior to this in the YoungMinds' report entitled "Two steps forward, one step back?" (Pugh and al. 2006) on 16-25 year olds' journeys into adulthood. In addition, the "Breaking the Cycle" report (Social Exclusion Unit 2004) also found that 98% of young adults (16- to 25-year-olds) accessing services in the UK had more than one problem or need, which included homelessness, problems associated with leaving care, mental ill-health, lack of training/education opportunities, barriers to employment, crime, poor housing, drug and alcohol misuse and learning disability.

In relation to the recommendations that transition should be person-centred, Sir Kennedy, in his review of children's services reported that services are currently failing to consider the particular needs of adolescents as they transition into adulthood (Kennedy 2010), a finding that is consistent with earlier studies and reviews suggesting that services pay inadequate attention to the things that are most important to young people at transition, such as friendships, social life and leisure (Heslop et al. 2002, Townsley 2004). Townsley (2004) in her review of information needs of young people with learning difficulties and their families at transition concluded that because of such inadequacies in service provision, it is not surprising to find that the outcomes of transition services are frequently so poor and that where positive outcomes have been achieved, with the young disabled person achieving "adult status" for example in terms of work and financial independent, this seems to be very much down to the role played by parents (Townsley 2004).

Coherent and multi-agency approach

Policy and professional guidance documents have strongly advocated coordinated working between professionals and agencies given the wide range of needs and multiple transitions that young people at healthcare transition are likely to experience (Department of Health 2004, Department of Health 2008, Lamb et al. 2008, National CAMHS Review 2008). However, studies have identified several gaps in partnership working between child and adult

health services, and other services which may need to be involved. These have suggested that adults' services may not be as integrated as children's services, which is problematic for young people who also require support with accommodation, education and training, employment and substance misuse issues (Aldridge and al 2008, Allen and Gregory 2009, Lamont et al. 2009, Singh et al. 2010b). Differences in organisational systems, for example, different computing systems and resulting difficulties in information exchange has been related to poor partnership working (Richards and Vostanis 2004, Singh et al. 2010b) in addition to different approaches to informal referrals, consent and confidentiality (HASCAS 2006).

In examining the transition from CAMHS to AMHS, the TRACK identified several problems in multidisciplinary working, for example lack of two-way communication between CAMHS/AMHS, inconsistent use of documentation, CPA approaches, different systems for information transfer, different cultural philosophies in CAMHS and AMHS, lack of confidence of AMHS in managing young people, lack of clarity, information and understanding between CAMHS and AMHS professionals on service structures, different thresholds and eligibility criteria for service access, few posts/limited funding for transition key-worker roles (Singh et al. 2010b). Singh and colleagues noted that in terms of content, the 13 active and two draft protocols investigated in their study, varied little in their underpinning principles, which were based on the National Service Frameworks (Department of Health 2004) however they were often different in practical aspects of transition, ranging from who was involved with their development to transition boundaries and the process of transition planning, including variations in expected joint working. For example, three-quarters of the protocols had no provision for ensuring continuity of care for cases not accepted by AMHS. Three protocols specifically mentioned a transition liaison worker and a single protocol mentioned the local availability of a consultation-liaison service but none mentioned a transitional service, although 16 respondents described themselves as 'adolescent' teams/service (Singh et al. 2010b). Several studies into physical healthcare transition have identified that continuity of care and better outcomes can be achieved if young people have ongoing relationships with one or a few healthcare professionals who have a role spanning both child and adult services or through having joint clinics involving paediatric and adult services (Allen et al. 2010, Dovey-Pearce et al. 2005, Klostermann et al. 2005, Nakhla et al. 2009, Shaw et al. 2004).

Furthermore, the TRACK study found that while many young people appear to make the transfer from CAMHS to AMHS, good transition does not occur (Singh et al. 2010b). Indeed, despite repeated efforts on the part of AMHS, the study identified that almost a fifth of service users referred to and accepted by AMHS are discharged without ever being seen; and less than five per cent of cases transferred to CAMHS experience optimum transition. Enduring mental illness severe enough to require admission to hospital and being on medication were the factors most likely to predict making a transition to AMHS. Continuity of care, i.e. being engaged with AMHS following transfer, was not predicted by these factors but instead was associated with having parents who are married or cohabiting. Importantly, those with emotional/neurotic and neurodevelopmental disorders were the least likely to achieve transfer to AMHS; and the former were the least likely to achieve continuity of care. These groups therefore seem to be doubly disadvantaged group in transitions and are the most likely group to fall through the CAMHS-AMHS gap (Singh et al. 2010b).

Neither CAMHS nor AMHS are entirely comprehensive and historically, CAMHS has been less focused on psychosis than AMHS, while AMHS has been less focused on developmental disorders. Tantom argued that CAMHS accepts responsibility for young people with ADHD and pervasive developmental disorders, but unless these young people can be fitted into the local learning disabilities services, there is simply no pathway for them to follow once they leave CAMHS, with AMHS arguing that they have no staff with the expertise to deal with them (Tantom 2005). This was confirmed by the findings of the TRACK study which showed that all protocols considered an 'enduring mental health problem' as an important criterion for referral to AMHS. Singh and colleagues noted that the term 'enduring mental health problem' seems to be a hybrid of the term 'severe and enduring mental illness', used by adult services, and 'mental health problems', a term used more in CAMHS, highlighting that stakeholders in the transition process may well hold differing conceptions of mental health, mental illness or disorder/problems (Singh et al. 2010b). Meanwhile, young people with mental health problems as understood in a developmental or CAMHS context may not fulfil the disorder/illness criteria used by AMHS for prioritising and targeting mental health care. This means that if an adult mental health service believes that neurodevelopmental disorders fall outside of this criterion then many individuals with ADHD, and other neurodevelopmental disorders such as autism and mild to moderate learning disability, are likely to fall through the care net (Young et al. 2011b).

Skills-training and measurable outcomes

Although it is widely acknowledged that for healthcare transition to be safe and effective it should be based on knowledge from research there is limited evidence available on best practice models (Crowley et al. 2011, Stewart et al. 2006, While et al. 2004). A lack of valid evaluation of transition procedures and practices, it has been argued, does not mean that planning and initiating of programmes which adequately prepare the young person for transition to adult care should not take place (Viner 2008). There is general recognition that key to preparing the young person for transition is equipping them with the skills to feel comfortable within the adult service. To aid this, methods of assessing readiness for adult care (e.g. being seen independently from parents, other evidence of self-advocacy, and condition and management knowledge) have received more attention recently (Fredericks et al. 2010, McPherson et al. 2009, Sawicki et al. 2011, van Staa et al. 2011, Williams et al. 2010). For example, Sawicki and colleagues (2011) have published preliminary validation data of the Transition Readiness Assessment Questionnaire, which appears to be useful both to assess transition readiness and to guide educational interventions by providers to support transition (Sawicki et al. 2011). Tools are also being designed for specific conditions, for example, the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence (Donkervoort et al, 2009). A recent systematic review identified that condition specific education resulted in positive clinical outcomes in four out of five studies, all relating to young people with diabetes, and that generic education and skills training were effective in two out of three studies. It also reported that in the UK, the Expert Patients Programme, originally for adults with chronic conditions, has now set up the young person equivalent called Staying Positive, which runs workshops created and run by young people for young people (Crowley et al. 2011).

There is also a general recognition that a lack of professional training in adolescent healthcare underpins the difficulty experienced by healthcare professionals in improving transition (Gleeson and Turner 2012, Kennedy 2010). Sir Kennedy argued that the problem with healthcare transition in the UK is that it has been viewed a process to get young people to adapt to healthcare professionals and the services they provide rather than healthcare professionals adapting to the needs of young people (Kennedy 2010). Indeed, in contrast to many other European countries, Australia, New Zealand, Canada and the U.S, adolescent health is not seen as a distinct specialty in the UK (Gleeson and Turner 2012). Several

surveys in the UK in children's hospital (McDonagh et al. 2006), among specialist trainees in paediatrics (Dieppe et al. 2008) and among healthcare professionals involved with transitional care in a specialty (McDonagh et al. 2004) report a lack of training in adolescent healthcare as a barrier to the delivery of transitional care.

Viner (2008) noted that the reasons for the neglect of adolescents in UK paediatrics is largely historical (Viner 2008). Paediatric services in the UK were largely a product of the foundation of the NHS and were built in response to concerns about infant and young-child mortality in the early part of the twentieth century. Since then the patterns of mortality and morbidity have changed considerably. The marked improvements seen in mortality rates of young children have not been matched by those of adolescents and mortality rates in older adolescents now outweigh that of the under fives. However, the training and focus of UK paediatricians, despite a recognition of the importance of chronic- illness management and multidisciplinary working, has up till now fundamentally retained the 1950s mindset that the business of paediatrics is prepubertal children (Viner 2008).

Nevertheless, there is some evidence that the deficit in adolescent health training in the UK is getting smaller. For example, Gleeson and Turner (2012) noted that experts have launched an e-learning package called the Adolescent Health Project (<http://www.e-lfh.org.uk/projects/ah/index.html>), a project that contains a wide range of modules divided into sessions, pitched at different levels to suit the educational needs of a variety of healthcare professionals working with young people. In addition, the Young Person's Health Special Interest Group of the Royal College of Paediatricians and Child Health (RCPCH) are seeking to embed adolescent health within paediatric training (Gleeson and Turner 2012).

3.8 Management of adults with ADHD in practice

As discussed earlier in this chapter, guidelines from North America (Canadian Attention Deficit Disorder Resource Alliance 2011), Europe (Kooij et al. 2010) and the UK (National Institute for Clinical Excellence 2008, Nutt et al. 2007) have advocated appropriate assessment and treatment of adult ADHD. One could therefore reasonably expect these to have had a significant effect on use of evidence-based treatments for adults with ADHD, especially in the UK. To date limited data is available on the treatment patterns of adults with ADHD in routine clinical practice. For this reason, some studies published before these

guidelines were published have also been included in this review to get a fuller picture of how adult ADHD is currently being managed in the UK.

Adult ADHD Services

Despite NICE recommendations, only a limited number of adult ADHD services have been established in the UK. The national Adult ADHD Clinic at the Maudsley Hospital in London is the longest running service that was set up in 1994 by Brian Toone and Susan Young, and currently offers diagnostic or treatment services for patients aged 18 to 64 (Asherson 2009). The clinic sees patients who were diagnosed with ADHD in childhood as well as those who were diagnosed in adulthood. Many of those diagnosed in adulthood are parents of children with ADHD who need additional help to provide effective support for their children.

Another established adult ADHD Clinic was based at the Addenbrooke's Hospital in Cambridge but was forced to close due to lack of NHS funding in 2011 (www.aadd-uk.org). Meanwhile, several other local NHS clinics for adults with ADHD have recently been established including: the Avon and Wiltshire Mental Health Partnership NHS Trust adult ADHD service, established in 2007, covering the Bristol areas; the South West Yorkshire Mental Health NHS Trust specialist adult ADHD service, established in April 2009, serving patients from the Midlands area; the Sheffield Adult ADHD service which is one of the first adult ADHD clinics integrated into general adult mental health services; the Leicester Adult ADHD service which has been operating since 2002; and the Lothian Adult ADHD service based at Royal Hospital Edinburgh Hospital, which is Scotland's first service that provides diagnostic assessments and treatments for adults with ADHD (www.cepip.com).

In addition to this, there are a limited number of private ADHD clinics in the country which treat and manage adult ADHD, including the Learning Assessment & Neurocare Centre (LANC) in Horsham, West Sussex and the Cambridge Adult ADHD Service, both of which see patients from all over the UK. The former is a multidisciplinary clinic that specialises in the management of children, adolescents and adults with complex neurodevelopmental difficulties, especially ADHD related conditions including Asperger's Syndrome, specific learning difficulties, dyslexia, Tourette Syndrome and emotional and behavioural problems. As many of these conditions interact and overlap, there is a great deal of emphasis placed on careful evaluation and subsequent liaison with schools and other involved organisations (www.lanc.org.uk/, www.cambridgeadhdclinic.com/adhd)

A national survey that assessed treatment of adult ADHD in England and Wales highlighted the lack of current services (Edwin and McDonald 2007). The survey asked all consultants in adult and child and adolescent psychiatry in England and Wales about the numbers of people with adult ADHD in their current case load and how many of these were treated. It found that only 19% of the consultants who responded offered a service for people with adult ADHD. The most commonly reported explanation for the lack of adult services for this clinical group was lack of funding or support from NHS trusts. A clear call for clinical guidelines (NICE) to be produced regarding the diagnosis and treatment of adults with ADHD was also made in this study in order to accurately diagnose and treat adults with ADHD.

Similarly, Marcer and colleagues (2008) investigated the experiences of 100 consultant community paediatricians across the UK about the transfer of patients with ADHD to adult care. They found that only 22% of respondents were aware of a dedicated clinic for adults within their area although a majority of them thought that a proportion of their patients would require referral to adult services. Many had tried to address this issue locally often with little success. The authors reported that they believe that this is in keeping with the general perception among some paediatricians that adult services are scarce and not sufficiently developed to meet patients' needs (Marcer et al. 2008).

Marcer and colleagues (2008) clearly identified a gap in the provision of health services for young people with ADHD on leaving paediatric care. Although some respondents were able to give examples of services that had been developed to meet this need, many more found that services did not exist in their area, or were difficult to access. Adult psychiatry services were identified as a common referral pathway, and yet there was a feeling that some of these services were ill-equipped or unwilling to take on such patients. Particularly, there was the view that adult psychiatrists locally seemed to not recognise ADHD as an adult disorder, making transition difficult. General practitioners were often perceived as inappropriate to manage young people with ADHD, lacking the skill or the interest. Some paediatricians felt that the problem may be in part resolved by young people taking themselves off medication at school leaving age (Marcer et al. 2008). This may be because they no longer seem to need it, or they are reluctant to see adult services, particularly psychiatrists, who may be perceived as stigmatizing.

The study by Marcer and colleagues (2008) demonstrates that services for adults with ADHD do not adequately exist at the present time, confirming the views of other researchers who have observed that adolescents with ADHD are currently leaving children's services often with no readily identifiable adult healthcare service to support them (Nutt et al. 2007). Marcer and colleagues urged that this be addressed as a matter of urgency to ensure appropriate treatment of a particularly vulnerable group of young adults (Marcer et al. 2008).

Information on the management of care for adults with ADHD also comes from the findings of the Adult Psychiatric Morbidity Survey (2007), a national survey of psychiatric morbidity among adults (aged 16 and above) living in private households in England (McManus et al. 2009). As part of the survey, data on mental health service use among those who screened positive for ADHD was collected representing the first national survey data of ADHD in England in the general adult population. It found that 8% of the adult population in England screened positively for ADHD characteristics, of whom 20% were receiving medication, counselling or therapy for a mental health or emotional problem. Antidepressant medication was the most widely used psychoactive drug. The survey also reported that none of the women who screened positive and only 0.2 % of the men screening positive for ADHD were currently taking Ritalin or Strattera, the two most commonly used medications for ADHD (although these were the only two ADHD medications asked about). This very low level of ADHD medication use was contrasted with a very high levels of antidepressant use among this group which indicated that while the great majority of people screening positive for ADHD do not access treatment or services, a higher proportion of this group access these for a mental or emotional reason, most likely reflecting the fact that adults screening positive for ADHD also have comorbid diagnoses with other psychiatric conditions or that their ADHD characteristics are being misdiagnosed by doctors not trained to recognise and treat adult ADHD (McManus et al. 2009).

Overall, the survey found that 80% of adults who screened positive for ADHD were not in receipt of medication, counselling or therapy for health or emotional problems. About one in three adults who had screened positive for ADHD (31%) reported using health services for a mental or emotional reason, compared with one in ten of those who had screened negative for the disorder (10%). The increase in reporting of community care and day care services among those screening positive was significant but less pronounced than health services used (McManus et al. 2009).

Given the lack of services for adults with ADHD, it has been suggested that they are often misdiagnosed and treated for other secondary problems (Lamberg 2003). Studies have shown, for example, that 20% of patients in drug and alcohol clinics may have unknown ADHD. Whilst treatment of secondary problems may be important, experts in the field of adult ADHD have noted that mis-specification of the diagnosis currently leads to inappropriate, ineffective and protracted interventions by psychiatrists and general practitioners as untreated people with ADHD are more likely to use more healthcare resources because of smoking related disorders, increased rates of serious accidents and alcohol and drug misuse (Asherson 2005).

Medication

Despite growing evidence showing the persistence of ADHD into adulthood, NICE reported in 2008 that a parallel growth in the prescribing of medication for adults with ADHD is not apparent. Instead the change in perceptions of adult ADHD and its treatment is only slowly filtering through to those engaged in treating the adult population (National Institute for Clinical Excellence 2008). A number of studies published in the UK have consistently highlighted that medication use to treat ADHD lessens with age once people with ADHD reach young adulthood. For example, Jick and colleagues (2004) reported a prevalence of 5.3 per 1000 of drug treated ADHD among boys aged 5 to 14 years in 1999 with the incidence of drug treated ADHD increasing from the age of 5 years to reach a peak at ages 9 to 10, after which the incidence rate decreased (Jick et al. 2004).

In another study by McCarthy and colleagues (2006) using the General Practice Research Database to investigate the numbers of patients and prescriptions for Methylphenidate, Dexamphetamine and Atomoxetine in adolescents and young adults with ADHD (aged between 15 and 21 years), the authors found that between 2001 and 2004 the number of patients and prescriptions for these drugs for ADHD had increased, but the prevalence of drug prescribing decreased as the patient became older (with a 35 fold decrease between the ages of 15 and 21 years). The steepest decrease occurred between the ages 16 and 17 reflecting the most common age when people are taken off their medication (McCarthy et al. 2006).

Furthermore, a longitudinal analysis in the UK that sought to determine the prevalence of Methylphenidate, Dexamphetamine and Atomoxetine prescribing and treatment

discontinuation in adolescents and young adults (Wong et al. 2009) demonstrated that 20% of patients were still receiving drug treatment for ADHD at 18 years but none of the patients continued to receive such treatment beyond the age of 21 years. As the drop in prescribing for ADHD was in excess of age-related decreases in symptoms, this raised the possibility that pharmacological treatment of some patients might have been stopped prematurely (McCarthy et al. 2009).

Taking into consideration recent research evidence which suggests that ADHD persists into adulthood in at least one third of patients, it is unclear whether many adolescents and young adults should be taken off medication when they could still benefit from it. A number of studies report that ADHD symptoms in adults show the same positive responsiveness to stimulant and non-stimulant medications as that seen in children (Faraone et al. 2004, Simpson and Plosker 2004). Despite this, a number of studies have raised the concern that general practitioners may be resistant to the use of stimulants on older people with ADHD.

The clinical and societal benefits of medication treatment among people with severe ADHD was highlighted recently in a large Swedish study that examined if those with ADHD had fewer criminal convictions when taking medication than when they were not (Lichtenstein et al. 2012). Using records of 25,000 patients with a diagnosis of ADHD, the study authors reported that when young adults with ADHD were taking medication they were less likely to commit crimes when taking medication. Although the study comprised adults with severe ADHD, many of whom had a history of hospitalisation, the authors reported that men were 32% less likely and women were 41% less likely to have criminal convictions while on medication. The authors therefore emphasised that in people with ADHD, especially young adults in prison or those who have left prison, medication use should be seriously considered given that it is more harmful for this group to be involved in criminal activities (Lichtenstein et al. 2012).

The fact that ADHD is still becoming recognised as a lifespan disorder means that many doctors may feel unfamiliar with prescribing medications to treat adult ADHD (Klasen and Goodman 2000, Kovshoff et al. 2012). Furthermore, expert diagnosticians of ADHD report that a more pragmatic concern may prevail in clinical practice, whereby busy psychiatrists and family practitioners may find it a nuisance to prescribe controlled drugs as prescriptions for these are known to take longer to write out (Asherson 2005). Moreover, premature

termination of treatment has been shown to be a significant problem in the general mental health field. The problem of dropouts has raised concern both about the unmet treatment needs of people and about inefficient use of existing resources. Patients who dropout may have higher initial levels of disturbance and achieve less improvement, compared to those who complete therapy (Armbruster and Kazdin 1994).

Premature cessation of medication treatment for young people with ADHD is especially unfortunate given that there is evidence that many young people themselves view their experiences with stimulant medication positively and identify a number of ways in which their medication helps them (Singh et al. 2010a). Singh and colleagues (2010) carried out a qualitative study in 9 to 14 year olds with ADHD and reported that young people found their stimulant medication to help them to calm down, to focus and concentrate, to think first before acting and not to feel angry and out of control. These beneficial effects had an associated positive impact on their ability to function at work/school, with friends and family members and helped them to form and maintain friendships and to manage their daily responsibilities. It therefore indicates that young people themselves believe that stimulant medication is an effective way to reduce impairments associated with ADHD. In addition, all young people interviewed in the Singh study believed that medication use was the most efficacious treatment for ADHD (Singh et al. 2010a).

A further in-depth qualitative study examining medication use by young people with ADHD was carried out by Wong and colleagues (2009) who sought to investigate the reasons, processes and outcomes of drug treatment cessation in young people with ADHD. The study found that from a clinical perspective, the reasons that patients decided to stop drug treatment were broad-ranging and included: (i) patient symptomology, (ii) side effects, (iii) inconvenience or dislike of taking medication, and (iv) stigmatisation. Meanwhile, the reasons for clinician-initiated cessation was attributed to: (i) lack of beneficial effect, (ii) side effects, (iii) non-attendance at appointments, and (iv) age of patient or length of time patient had been on medication and (v) the patient approaching the age where CAMHS are finishing where there is a lack of adult services. Furthermore, all the clinicians interviewed spoke of the difficulties that arose once an adolescent reaches the age where child and adolescent services are no longer available and described the provision of care to patients beyond the age limit set by CAMHS as very limited. Transfer to adult services was seen as problematic either because trusts would not commission services due to a lack of resources and guidelines or

because adult psychiatrists or GPs did not have appropriate training in ADHD diagnosis and management, had competing priorities, were unwilling to prescribe unlicensed medications, or had a belief that the condition does not exist in adulthood (Wong et al. 2009).

Furthermore, the study (Wong et al. 2009) found that none of the clinicians interviewed had any formal guidelines or protocols in place for cessation. However, the process characteristically involved four key stages: preparation, choosing an appropriate time, commencing cessation, and a period of monitoring and follow-up. With regards to timing, clinicians had different ideas about what constituted an appropriate time to attempt cessation, be it the patient's age, whether they were still in full-time education, or the length of time they had been on medication. Although some clinicians preferred to reduce doses gradually, the majority decided on a specific time (with the patient and their family) when the patient would stop taking all doses. Both clinicians and patients used drug holidays as a way of seeing how patients would get on. Patients felt that this provided them with an opportunity to see how they would manage without medication and had given them the confidence to attempt a more prolonged period of cessation. Timing of follow-ups and frequency varied, but most clinicians would offer a follow-up session shortly after cessation was initiated, with another follow-up consultation further down the line. Support during this time was mainly provided by the patient's main clinician, although some had access to community psychiatric nurses, a family support worker, a family coach, educational services and cognitive-behaviour therapists (Wong et al. 2009).

Psychological treatments

Despite the clinical recommendations that optimal treatment of ADHD should involve a comprehensive care package, usually consisting of both pharmacological and non-pharmacological (e.g. psychological) treatments, the evidence suggests that psychological treatments are not routinely offered to adults with ADHD and that the use of psychological interventions for ADHD is, in all probability, variable. It is likely that the pattern of the availability of psychological interventions varies according to locality and the resources within that locality. NICE reports that much will also depend on the individual diagnosis, with a care plan being tailored to each individual's needs rather than a universal intervention package being offered within each setting (National Institute for Clinical Excellence 2008).

According to NICE (2008), psychological therapies, if used, are usually used as additional to treatment with medication. As young adults mature and their symptoms remit however, and treatment with medication may no longer be recommended, a need for psychological treatment may continue, if not arise, to address feelings of helplessness and low self-esteem (National Institute for Clinical Excellence 2008). Both individual and group CBT are routinely offered at the Adult ADHD clinic at the Maudsley Hospital to help patients go through a process of adjustment in coming to terms with their diagnosis and the impact of the disorder on their lives and are used subsequently to a focus on the treatment of comorbidities and skills deficits (Young et al. 2008). Increasingly, ADHD coaching has also been used by adults with ADHD to help people develop strategies to deal with challenging situations. These have been used as an adjunct to cognitive group programmes for adults with ADHD (Stevenson et al. 2002).

3.9 Chapter summary

The literature on healthcare service use for those with ADHD who no longer qualify for children's and adolescent services, suggests that there is an urgent need for more health services for adults with ADHD. There is currently a serious risk of disruption in care provision for adolescents and young adults with a childhood diagnosis of ADHD who continue to need support from health services. This is in discord with the increased emphasis at public policy level regarding the importance on providing continuity of care for those with continuing needs and on the importance improving service provision for this group. To improve recognition and treatment for this group, it is crucial to comprehensively examine what the needs of this group are and to what extent services and family/or friends are currently meeting these needs. In addition, a better understanding of the factors associated with health service use in this group and how young people and families experience healthcare transition can inform service providers and policy makers on how to better for this group.

The next chapter describes the theoretical and conceptual framework used in this study.

CHAPTER 4

Theoretical and conceptual framework

4.1 Introduction

This chapter reviews the conceptual framework used in this study and the literature on correlates of health service use among young people (adolescent and young adults) with mental health problems before focusing on reviewing the literature on the correlates of health service use among those with ADHD. For the purposes of this thesis, the literature concerning children and older adults has been excluded although, where appropriate, literature relating to other age groups may be included in order to draw age comparisons. Before these two reviews, however, a brief conceptual overview of needs, health service use and healthcare transitions is given, exploring how these terms have been defined and conceptualised in the previous mental health literature. As there is substantial literature relating to the conceptual issues around the use of these terms, the aim here is to give a selective rather than exhaustive review.

4.2 Conceptual overview of needs, service use and healthcare transition

4.2.1 Needs

A wide variety of definitions of “need” have been developed. In the context of health services “need” has been defined as a “problem which can benefit from an existing intervention” (Stevens and Gabbay 1991). Also, the Department of Health defined need as “the requirement of individuals to enable them to achieve, maintain or restore an acceptable level of social independence or quality of life” (Department of Health Social Services Inspectorate 1991). In this latter definition two types of need can be present: met need (difficulties that are ameliorated through help given), and unmet need (where a problem currently exists, whether or not any help is given). The fact that a need is identified does not mean that it can be met. For example, needs may remain unmet because other problems take priority, because an effective method is not available, or because the person in need refuses treatment.

The idea that “need” should include a wide range of life domains was upheld by Asadi-Lari and colleagues (2003) who argued that in addition to healthcare “need” ought to include a wide range of characteristics such as personal and social care, accommodation, finance, education, employment and leisure, transport and access (Asadi-Lari et al. 2003). The wider the definition of needs, they argued, the more important implications it has for healthcare provision and more care is available (Asadi-Lari et al. 2003).

In the field of mental health, several operationalised assessment tools exist in the assessment of needs, of which the Camberwell Assessment of Need (CAN) (Phelan et al. 1995) has rapidly become the research tool of choice. It was originally developed for the assessment of needs in people with severe mental illness and has since been adapted for use with people with developmental disorders (Camberwell Assessment of Needs for Adults with developmental and intellectual disabilities, CANDID) (Xenitidis 2003). Both the CAN and the CANDID measure a wide range of needs and are guided by four broad principles:

- (i) Everyone has needs and although people with mental health problems have special needs the majority of their needs are essentially similar to those of people without mental health problems.
- (ii) People with mental health problems often have complex needs in a number of life domains. It is therefore important to identify, rather than describe in detail, the person’s needs. More specialised assessments can then be conducted in areas where a need has been identified.
- (iii) Routine clinical use and service evaluation are two different but equally valid uses of a needs assessment tool, which therefore needs to be useable by a wide range of professionals.
- (iv) Need is a subjective concept and the perspectives of various stakeholders may differ. This is why the views of the users and those who care for them should be recorded separately (Xenitidis 2003).

The idea that needs should be identified in a variety of different life domains has been established as a driving principle of modern mental health service delivery and underpins care planning (Department of Health 1999). In 1990 the government created the NHS & Community Care Act which stressed the importance of assessing a range of needs of those residents in the community who may require help (House of Commons 1990). Moreover,

needs assessment is also necessary from a health economics perspective as there is an increasing awareness of the limited resources available to health and social care. Indeed, there has been a growing recognition among practitioners and policy-makers in recent years of the requirement to provide health and social services according to need. This is to allow rational use of limited resources and ensure provision of comprehensive services. Current legislation has already been developed to support this practice and to shift care provision from service-led or demand-led to needs-led, leading to the creation of many “needs assessment” instruments.

It should also be noted that in epidemiological research, the concept of “unmet need” has become important in investigations into service use. It refers to the discrepancy between the level of disorder and service use and it has been argued that it is a more relevant concept than simply reporting the use of services (Flisher et al. 1997). Unmet need may be defined “objectively” as the proportion of individuals who meet criteria for a disorder but do not seek professional care (Katz et al. 1997). This definition has been criticised as both insufficiently and overly inclusive. For example, some individuals who meet diagnostic criteria for a disorder may not experience sufficient impairment or distress that they perceive a need for treatment (Aoun et al. 2004, Wang et al. 2004). Conversely, individuals may experience severe distress, perceive a need and seek services in the absence of a diagnosable disorder (Katz et al. 1997). Others who are symptomatic and impaired with diagnosable disorder perceive a need, but nevertheless do not seek mental health treatment (“perceived” or “subjective” unmet need) (Aoun et al. 2004, Katz et al. 1997).

Moreover, people with impairing psychopathology or illness may be in contact with services that may not be able to provide an effective intervention for their difficulties making their needs “unmeetable” (Harrington et al. 1999). Thus, it is not appropriate to assume that the presence of impairing psychopathology in the absence of service contact adequately identifies unmet need as some investigators have done, as this assumes that all people currently in contact with services have all their needs met (Flisher et al. 1997). Therefore, it is important to assess if support is received from informal networks (such as family and friends) and formal services and if the amount and type of support received is judged as sufficient and appropriate by the person who is assessed.

Given the divergences between objective and subjective indices of need, consideration of both domains is important in assessing the adequacy of mental health service availability (Aoun et al. 2004). Reduction of both objective and subjective unmet need for mental healthcare, especially among young people who meet criteria for a mental health disorder, remain key goals of public health policy (National Institute for Clinical Excellence 2008). A greater understanding of the extent, distribution, and determinants of subjective unmet service needs may inform efforts to expand service access to target groups.

As one of the underlying principles behind the CANDID, need is a subjective concept and the views of various stakeholders may differ. Therefore, it may be, for example, that for young people with ADHD, the needs that concern them the most are not the core symptoms of ADHD or any needs directly associated with ADHD, but for example, problems with social contact which may also be influenced by other factors such as drug abuse or a comorbid disorder. Conversely, parents of these young people may view other needs, such as those regarding inappropriate behaviour or communication as the most concerning needs because of their different perspective.

Similarly, when assessing needs in one person, several perspectives may be important in order to get a fuller picture of their needs. The person with the needs may, for one reason or another, under or over estimate their needs or not recognise that they have problems in certain life areas. Another person, such as a mother, who is assessing this person's needs may recognise that the person has significant needs and should be able to look after themselves or look after themselves better, when comparing the level of development of their peers or others without the disorder.

In summary, several definitions of needs exist which underlie the needs instrument used in this study. Assessing service use and needs in people with ADHD to determine not only services used but also the met and unmet needs of people in this group will help inform policy makers of effective care programmes for young people with ADHD. The term “service use” will be reviewed next.

4.2.2 Service use

The term “service utilisation” is usually reserved for when individuals actually receive services or interventions. It needs to be distinguished from “service provision” (or supply)

that is used to refer to when services are offered, whether they are used or not. As stated by Gulliford and colleagues (2002) the terms “service use” and “service provision” are often used inter-changeably, with the implication that the latter term may wrongly be assumed to mean services that are offered and also being used. As researchers have begun to unravel the determinants of service use they have discovered that there are several factors that may impede service use. Services may be provided but for some reason are not easily accessible to the person who would benefit from the service and who wishes to use them. Similarly, in other cases services may be offered but are not used (e.g. refused) by those who they were designed for (Gulliford et al. 2002). In addition, not all young people with disorders require services (for example, some disorders may be self-limiting), whereas some young people with symptoms or an impairment not meeting criteria for a disorder may benefit from services, while interventions for some disorders, such as autism, may alleviate but not remove “need” as defined by the presence of symptoms and impairments (Jenkins 2001). Nevertheless, epidemiological approaches are generally acknowledged as helpful in identifying the prevalence of impairing psychiatric disorder in the community, a prevalence which may be used as a proxy indicator of the level of “need” for services (Jenkins 2001).

Service use should also be distinguished from “access” (to care) which is a related term often used in healthcare research. Access is a key term used in recent UK government policy papers, with the government proposing that “patients will get fair access to consistently high quality, prompt and accessible services right across the country” (Department of Health 2001). In an early discussion on access, Aday and Andersen (1975) suggested that “it is perhaps most meaningful to consider access in terms of whether those who need care get into the system or not” (Aday and Andersen 1975). They suggested that access can be used to describe either the potential or the actual entry of a given individual or population group into the healthcare system (Aday and Andersen 1975). Thus “having access” denotes a *potential* to utilise a service if required, whereas “gaining access” refers to the *initiation* into the process of utilising a service.

Related to the concept of service utilisation is the concept of “service availability” which encapsulates the assumption that there is an adequate supply of health services available. The “availability of services” is related to the resources of communities and governments and is traditionally measured using indicators such as hospital beds or doctors in hospitals per capita. There are large variations in England between districts in the numbers of general

practitioners per head of population, the proportion of the population registered with dentists, or the proportion accessing specialist surgical services (Department of Health 2001). There is great debate as to the resources required for healthcare and the methods used to allocate resources to different geographical locations (Haynes et al. 1999) and these resource allocations will clearly have significant impact on service utilisation.

Therefore, the term “service use” needs to be distinguished from “service provision”, “access to care” and “service availability”. As Gulliford (2002) reports, “service use” should be reserved for when an individual actually uses care as opposed to when services may be provided but are not used by the person they were designed for (Gulliford et al. 2002). Indeed, it is helpful to think of service use as the end result of service provision, service availability and access to services by those for whom the services are intended.

Researchers who have chosen to study service use for mental health problems have also frequently failed to define the type of services they are trying to investigate (Sayal and Ford 2010). For example, some have defined the concept “services” broadly, including help-seeking behaviours and informal discussion with peers to inpatient mental health services. Others have attempted to narrow the operational definitions of services, but a lack of consistent terminology persists. Sayal and Ford (2010) noted that studies have commonly combined “any service use” (e.g. any type of services used) and “contact with specialist mental health services” (Sayal and Ford 2010), leading to inconsistent findings regarding factors associated with service use. Indeed, many large epidemiological studies have examined the correlates of the combined use of services, including services such as paediatrics or social services together with mental health services, or have failed to define what specific services they were studying (Almqvist et al. 1999, Anderson et al. 1987, Feehan et al. 1990).

For the purposes of this thesis, the studies included in the literature review maintain a focus on health services delivered by paediatricians, primary care, child/adolescent and adult mental health services. Attempts will be made to distinguish findings involving health services provided by mental health specialists specifically from those incorporating health services offered through other health professionals such as primary care physicians or paediatricians.

4.2.3 Healthcare transition

As discussed in Chapter 3, the concept of healthcare transition first emerged two decades ago as a way of improving health service provision for those young people with continuing healthcare needs who had outgrown child services. Since then the past two decades have seen continued attempts to define and describe healthcare transitions. As discussed in Chapter 1, while some researchers have defined transition from a broader developmental perspective, (Beresford, 2004, p. 584) this thesis is mainly concerned with a healthcare perspective of transition while acknowledging that healthcare transition is merely one part of a range of educational, personal, family and social transitions that young people make during adolescence (Viner, 2008).

Within this healthcare perspective, one of the first definitions of healthcare transition was given by the Society for Adolescent Medicine (SAM) in the US (since renamed Society of Adolescent Health and Medicine (SAMH)), who in 1993 defined healthcare transition as “a multi-faceted, active process that attends to the medical, psychosocial and educational/vocational needs of adolescents as they move from child to adult-centered care” (Blum et al. 1993, p. 570). This definition had a remarkable impact on major UK policy documents which can be seen, for example, in its reference by the Royal College of Paediatrics and Child Health (RCPCH) in 2003 and by the UK Department of Health, Child Health and Maternity Services Branch (DH-CH-MSB) in 2006 (Viner, 2008). Ten years later, in 2003, SAMH defined healthcare transition as “a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health-care systems” (Rosen et al, 2003), which has been commonly referred to as the “standard definition” of transition (Viner, 2008).

The definitions by SAM/SAMH stress the importance of viewing transition as a process rather than an event reflecting a general agreement that healthcare transition should amount to more than just a simple transfer (e.g. a termination of care by a children's healthcare provider and its re-establishment with an adult provider) (McDonagh & Kelly, 2003). While some have discussed transfer as a suboptimal version of transition (Kennedy, 2010) others have argued that healthcare transition should, in fact, be seen as distinct from transfer although the two are related concepts (Paul et al. 2013). Indeed, Paul and colleagues, in

reviewing the findings of the TRACK study of healthcare transitions in the UK, argued that transition is a process requiring therapeutic intent, which may be expressed by the young person's preparation for transition, a period of handover or joint care, transition planning meetings (involving the young person and carer, and key CAMHS and AMHS professionals) and transfer of case notes or information summaries (Paul et al. 2013). They noted that transfer can be of use even if transition has been poor whereas transition processes and policies may be followed impeccably yet still result in failure to transfer (e.g. if the patient chooses not to go to adult services for some reason) and so the two should be examined separately.

Underlying the concept of transition, when viewed from this healthcare perspective, is the idea that the move from child to adult services should involve “continuity of care”. One widely cited review by Haggerty et al (2003) on the continuity of care propose the following key definitions of the term: (i) it is an aspect of care experienced by persons receiving care, for services received over time; (ii) it involves the patient’s experience of consistency, smoothness, and coordination in care; and (iii) it relates to how patients/clients experience integration of services and coordination among providers (Haggerty et al. 2003). Haggerty and colleagues (2003) also delineated three main dimensions of continuity: relational continuity, defined as an ongoing therapeutic relationship between a patient and one or more providers; informational continuity, defined as the use of information from prior events and circumstances to make current care appropriate for the individual and his or her condition; and management continuity, defined as the timely provision of services that complement each other within a shared management plan, delivered by a variety of providers. Management continuity emphasizes the use and consistent implementation of care plans, especially when patients cross organizational and service boundaries (Haggerty et al. 2003). Care plans are important tools for bridging current and past care and for arranging for future needs and should remain flexible to accommodate changes in patient’s need and circumstances (Bass and Windle 1972).

Continuity of care in mental health service provision is increasingly recognised as a key aspect of service provision (Crawford et al. 2004, While et al. 2004). Indeed, continuity of care is a particularly important issue in the evaluation of services treating disabling chronic conditions. Patients are increasingly seen by a range of service providers in a wide variety of places, raising concerns about fragmentation of care. Policy reports worldwide urge a

concerted effort to enhance continuity (World Health Organization 2003). Confusingly, other terms are sometimes used to refer to continuity of care, such as continuum of care, coordination of care, discharge planning, case management, integration of services, and seamless care (Haggerty et al. 2003).

Providing patients with a sense that the various elements of their health services are connected over time and place is a key component of improving healthcare for persons with chronic health conditions (Miller et al. 2009). The mental healthcare literature emphasises coordination of services and the stability of patient-provider relationships over time. Unlike primary care, the relationship is typically established with a team rather than a single provider. That is, care provided by different professionals is coordinated through a common purpose and plan (Tessler et al. 1986).

To summarise, the term “transition” encompasses several perspectives and may be viewed as a healthcare process involving the move from child to adult health services or as a broader developmental move from one life stage to another. As noted in Chapter 1, this thesis views transition from a healthcare perspective and defines transition as the process of moving from child to adult health services involving both a period of preparation for the transfer to adult care and the transfer itself.

The next section will review Andersen’s behavioural model, which was used to approach research objective (ii) in the present study.

4.3 Review of the Andersen’s behavioural model of health service utilization

This study used Andersen’s behavioural model of health service utilisation (Aday and Andersen 1974, Andersen 1968, Andersen 1995, Andersen and Newman 1973) to address health service use in young people with ADHD at transition from childhood to adulthood. Andersen’s behavioural model (often referred to as the “health service utilisation model”) is one of the leading theoretical models of health service use and was designed specifically to investigate variance in general health service utilisation (Andersen 1968). However, it has also been applied to examine correlates of specialist mental health service use (Bergeron et al. 2005, Cairney et al. 2004, Drapeau et al. 2005, Goodwin and Andersen 2002).

Andersen first introduced this model in the late 1960s following an extensive nationwide face-to-face interview survey on health service use among a large sample of families in 1964 in the US (Andersen 1968). The survey was conducted because there was concern at the time over the unfair distribution of healthcare use among the population, with some sectors of society thought to receive fewer health services than others (Andersen and Newman 1973). Andersen and colleagues therefore set out to examine inequalities empirically in health services use in the hope that their findings would lead to policies that would promote equitable access to healthcare in the US (Andersen 1968).

In his original study, Andersen examined the use of three types of health services: hospital, physician and dental services (Andersen 1968). The model described three categories of variables that were thought to influence service use: predisposing, enabling and need factors. It assumed that a sequence of factors determined the use of health services: the predisposition to use services, the ability to use services, and the need to use services. In discussing causal pathways, Andersen (Andersen 1968, p. 19-20) formulated and tested three major hypotheses regarding the relationship of these predisposing, enabling, and need components and health service use. First, he hypothesised that the amount of health service used by a family was a function of the predisposing and enabling characteristics of the family and its need for medical care. Each of these three components was hypothesised to make an independent contribution to understanding differences in health service use. Second, he hypothesised that the explanatory components of the model would vary in their contribution to the explanation of total use. For example, need would be more important than the predisposing and enabling components because it captures factors most directly related to service use. Third, Andersen believed that the contribution of each component would vary according to the type of health service used, for example (i) the contribution of need would be greatest for hospital services; (ii) all of the components would be important for understanding physician services and (iii) the contribution of the predisposing and enabling components would be greatest for dental services (Andersen 1968).

Andersen's hypotheses were well supported by his empirical findings. Andersen (1968) found that his service model accounted for 27% of the variance in the use of hospital services; 47% of the variance in the use of physician services; and 19% in the use of dental services. As hypothesised by Andersen, hospital services were largely predicted by need

factors, physician service use was predicted by all three (predisposing, enabling and need) variables and dental services were predicted by predisposing variables and income.

Andersen's seminal 1968 study focused on the family as the unit of analysis and hence several family-level variables were considered (Andersen 1968). Later versions of the model focused on the individual as the unit of analysis (Andersen and Newman 1973) and therefore these family-level factors were discarded. As a result changes were made to the predisposing, enabling and need factors. Within the predisposing factors, the demographic characteristics (no longer called 'family composition') were for example, age, sex, marital status and past history of illness. The enabling characteristics were race, ethnicity, occupation, family size, religion and residential mobility. These enabling factors were similar to factors in the original model but were measured at the individual level rather than the family level. The need factors were divided into perceived and evaluated needs. The perceived need was composed of self-rated disability, symptoms, diagnoses and general health. The evaluated need was official recognition of symptoms and a diagnosis from a medical practitioner.

As well as the individual characteristics, the 1973 adaptation added additional enabling factors to the model. These included availability of support and the level of health technology (on a societal level) (Andersen and Newman 1973). These were considered an improvement on the original model which had considered ratios of physician to population and hospital bed to population as enabling factors (Andersen 1968). These enabling factors were now moved out of the individual level to the societal level, highlighting that service use was determined not only by the individual's decisions and place in society, but also by the organisation of the society within which individuals live.

In 1995 Andersen summarized the development of the model and addressed the criticism that the model had received (Andersen 1995). He presented a new version of his model, still based on the concept of the three groups of predisposing, enabling and need factors. He added health behaviour and patient satisfaction as important factors that can determine service use as patients' experiences of past service use can influence their perception of the quality of care. This is important in understanding the relationship between quality of care and the use of services. Feedback loops (reciprocity or simultaneity) were added to the model in 1995 in order to take into account that individual characteristics in the model can influence

utilization and vice versa (Andersen 1995). The next section will now further discuss how predisposing, enabling and need factors were thought to influence service use.

4.3.1 Predisposing, enabling and need factors

Predisposing variables included those that described the propensity of family members to use health services and were based on the theory that certain family characteristics preceded the illness and made health service use more likely. These characteristics were: family composition, social structure, and health beliefs (Andersen 1968). First, family composition factors included age and sex of family members, family size and ages of oldest and youngest family members. Second, social structure factors included employment, social class and occupation of the main wage earner as well as education, ethnicity and race of the family head. Finally, the health beliefs factors included the value of health services, doctors, good health and health insurance; attitudes toward doctors and health services; and knowledge of disease. For example, people who believe strongly in the value of healthcare or doctors may be more likely to seek care than those who do not have these beliefs.

The enabling factors in Andersen's behavioural model were based on the idea that even if a family has a predisposition to use health services, certain characteristics (such as parent level of education) may make use of health services more likely. Both resources specific to families (income, savings, and health insurance) and attributes of the community in which they live (ratios of doctors and hospital beds, residence, and region) were included (Andersen 1968). Place of residence, e.g. whether one lives in a rural or urban area, may indicate geographic proximity to a source of care as well as prevailing community attitudes toward medical care.

Need variables in Andersen's behavioural model referred to health status or illness, based on the theory that in order for a health service to be used, there must first be a need to use that service. Therefore, need factors were seen as the most important and most immediate cause of health service use. Andersen (1968) described two types of need factors: illness variables and response variables (Andersen 1968). Not only must the family recognise that there is an illness, but they must also respond appropriately in order to use services. The illness variables were self-reported health level, symptoms, and number of 'disability days'. The response variables were visiting a doctor and having regular physical examinations.

4.3.2 The strengths and limitations of the Andersen's model

A wide variety of models have attempted to describe and conceptualise the process of help-seeking which although different in content and emphasis share some common features (Aday and Andersen 1974, Andersen 1995, Andersen and Newman 1973, Biddle et al. 2007, Fischer et al. 1983, Goldberg 1980, Goldberg and Huxley 1992, Pescosolido 1991, Rickwood et al. 2007, Rosenstock et al. 1988, Verhulst and Koot 1992). They all assume help-seeking to be a stage-like process during which the progress on the pathway to care is influenced by other variables that can either obstruct or facilitate progress through the various help-seeking stages. For example, Fischer, Weiner, and Abramowitz (1983), suggested that an individual obtains help by proceeding through the following five-step sequence: (a) perception/identification of the problem; (b) contemplation of options; (c) the decision to seek help; (d) the experience of a precipitating event that mobilizes the individual to follow through on help-seeking intentions and (5) overt help-seeking (Fischer et al. 1983).

Although the Andersen's model is considered a help-seeking model, its primary focus is on factors that influence actual health service use (that is, the last stage of the help-seeking process) rather than the earlier stages such as people's perceptions of symptoms or the decision to seek help. This focus means that the Andersen's model places less emphasis on the cognitive factors that influence decisions to seek help and more importance on differences in the characteristics of health service users and non-users. Andersen's behavioural model is concerned with *if* health services are used or not rather than *when* and *how* health services are received (and the factors associated with this).

Perhaps the most distinctive feature of the Andersen's model is its description of health service use as being determined by predisposing, enabling and need factors. In placing emphasis on how predisposing, enabling and need factors influence health service use it is able to explain why active help-seeking does not necessarily lead to actual use of health services even when all the other stages of the help-seeking process have been met. For example, a young person with mental health problems may have perceived and identified that he or she has a problem; contemplated all the options; made the decision to seek help; followed through on help-seeking intentions and overtly sought help but been hindered from actual health service use because he or she did not know where to go for services or found that no suitable health services were available in his/her geographical area. Such enabling

characteristics may therefore ultimately mean that health services are not used despite help-seeking intentions and overt help-seeking behaviour.

However, perhaps one of the greatest strengths of Andersen's model is its flexibility as it does not specify the variables which must be used to operationalise the predisposing, enabling and need factors (Andersen and Newman 1973). Instead, the choice of variables, within the framework of predisposing, enabling and need factors, is up to each researcher and the particular theoretical relationship between specific independent and outcome variables. Therefore, it is possible to adapt the Andersen's model to suit additional factors found in adolescent models such as the one by Verhulst and Koot (1992). In doing so it is possible to include both young person and parent/family characteristics along with the predisposing, enabling and need domains as laid out in the Andersen's model. Indeed, with the Andersen's model each researcher can choose their own independent variables depending on their own study's theoretical rationale. This and other characteristics of the model have led several researchers to emphasise the usefulness of applying Andersen's behavioural model to examine need, enabling and predisposing factors associated with health services use (Phillips et al. 1998, Wolinsky et al. 1983).

4.4 Correlates of health service use for mental health problems among adolescents and young adults: a review of the literature

Several studies have highlighted that despite the availability of effective treatments, only a minority of those with mental health problems are in receipt of professional help (Patel et al. 2007, Wittchen et al. 2011). For example, a recent academic policy report reporting on the state of mental health services in Britain revealed that only a quarter of people under 65 years who have a mental health problem are currently receiving any treatment (LSE 2012). A preference for turning to family or friends and teachers before seeking help from mental health professionals has been suggested as one possible explanation for this finding (Ford et al. 2008, Haines et al. 2002, Rickwood et al. 2007). Even among young people with mental health problems who do attend health services, the tendency is to do so because of physical rather than mental health reasons (Garraalda and Bailey 1986, Giel et al. 1981, Gureje et al. 1994). Consequently, many mental health problems go unrecognised by health services (Garraalda and Bailey 1986, Glazebrook et al. 2003, Sayal 2006).

A wide discrepancy between need for evidence-based treatments and use of health services is arguably most concerning among those aged 16 to 24. Compared to other age groups, the 16 to 24 year age group has been identified in national surveys to have the highest rate of mental disorders (Andrews et al. 2001, Bijl et al. 1998, Kessler et al. 1994), however they are the least likely to seek help from health services because of mental health problems (Andrews et al. 2001, Olfson and Klerman 1992). Rates of health service use among those with mental health disorders in this age group vary due to methodological differences but have generally been reported to lie between 17-35% (Aalto-Setälä et al. 2002, Bergeron et al. 2005, Kessler et al. 2005, Newman et al. 1996, Patel et al. 2007, Rickwood and Braithwaite 1994, Vanheusden et al. 2008). Low rates of health service use among adolescents and young adults are of particular concern because of increased rates of suicide among men in this age group and its association with negative coping strategies, such as deliberate self-harm and alcohol use (Hawton et al. 2003). Negative perception of help-seeking also contrasts with the evidence for effective treatments for a range of mental disorders in both adolescent and adult populations (Malouff et al. 2007). However, conversely, the negative perception of help-seeking is in agreement with the notion that existing mental health services fail to appeal to young adults (Patel et al. 2007).

4.4.1 Search strategy

To identify relevant research material on correlates of health service use among young people (adolescents and young adults) with mental health problems, PsycInfo, Web of Knowledge, Medline and Scopus databases were searched from 1992 up to September 2012. The search terms used were “healthcare utilization” OR “help-seeking” AND “mental” OR “mental disorder” OR “emotional and behavioural problems” AND “adolescent” OR “young adult” OR “young people”. Where possible, the searches were limited to “<age 13 to 17 years (adolescence)” or “<age 18-29 years> (young adulthood)”. This combined search strategy yielded 1204 papers. After removing duplicates, the titles and abstracts of the remaining 420 papers were screened according to inclusion and exclusion criteria. Studies that did not discuss factors that were associated with either help-seeking or health service use were excluded as were those that focused on physical health problems rather than mental health problems. This resulted in 54 studies to be reviewed. An additional 18 studies were located through hand-searching the reference lists of key papers found through the systematic search described above. This yielded a total of 72 papers for possible inclusion in the review.

4.4.2 The role of predisposing factors on adolescent and young adult health service use for mental health problems

Andersen (1995) hypothesised that in the presence of need for services, predisposing forces exert an influence on health service use. As discussed earlier in this Chapter, predisposing characteristics are demographic factors or other individual characteristics that exist prior to the onset of disease and affect a person's willingness to seek services. They reflect people's tendency to seek services and include socio-demographic factors such as age, gender and beliefs about services and obtaining professional help.

Although very few studies have examined factors associated with health service use among young adults with mental health problems specifically, those that have consistently report a gender effect on service use whereby young males are particularly unlikely to seek help for mental health problems (Aalto-Setälä et al. 2002, Bergeron et al. 2005, Biddle et al. 2004). Biddle and colleagues (2004), for example, who conducted the first British study to focus specifically on the help-seeking behaviour of mentally distressed young adults, found that even when young adult males perceived themselves as having a mental health problem they were especially unlikely to seek help from their GP (Biddle et al. 2004). Similarly, in their examination of determinants of help-seeking behaviour among young people (aged 15-24 years) with a mental health problem in Canada, Bergeron and colleagues (2005) reported that only 25% of young Canadians with an anxiety, depressive or substance use disorder had sought formal or informal help, and significantly lower rates were found in males (Bergeron et al. 2005). Why young males are less likely than young females to use services for mental health problems is not clear but it has been suggested that the traditional masculine role discourages men to admit that they need professional help for emotional problems (Møller-Leimkuhler 2002).

Studies comprising children and adolescents with mental health problems, however, generally report no gender effect in relation to health service use. Those that do mostly report a preponderance of boys in contact with mental health services (Angold et al. 2002, Briggs-Gowan et al. 2000, Wu et al. 1999, Zahner and Daskalakis 1997, Zwaanswijk et al. 2003). A complex association between gender and age has also been reported among children and adolescents (Cohen and Hesselbart 1993, Gasquet et al. 1999, Laitinen-Krispijn et al. 1999, Sourander et al. 2004). While some authors have reported that help-seeking increases among boys in middle to late adolescence but not among boys in early adolescence (Gasquet et al.

1997) others have reported a decrease in mental health service use among boys in late adolescence (Cohen and Hesselbart 1993). Sourander and colleagues (2004), for example, argued that boys in late adolescence may have especially critical views of health services compared with boys in middle and early adolescence and that parents and teachers are more likely to initiate health service contacts among younger adolescents. Unfortunately, Sourander and colleagues did not collect data on adolescents' own perspectives of mental health services and were therefore unable to test this hypothesis (Sourander et al. 2004).

Other studies have however indicated that perceptions of services, such as lack of trust; reluctance to discuss problems with a professional; views of others; and thinking that treatment may be inappropriate, unhelpful, or harmful may play a significant role in influencing health service use among young people with mental health problems (Rickwood et al. 2007). For example, Owens and colleagues (2002) reported an association between parents' perceptions of services and children's and adolescents' service use for mental health problems (Owens et al. 2002). Similarly, among young adults, predisposing factors such as attitudes towards general practitioners (Biddle et al. 2006) and mental health professionals (Parslow and Jorm 2000) may predispose some to consult these professionals while discouraging others.

Biddle and colleagues (2006), who conducted a qualitative study exploring young adults' perceptions regarding their GPs as a source for mental distress, identified that most young adults did not value or recognise GPs as a source of help for mental disorder or distress. Instead, the young adults in their study tended to think that GPs deal exclusively with physical illness, lack training in mental health, are unable to provide "talking" therapy, and may be dismissive of those consulting with mental distress. Furthermore, a prescription for antidepressants was seen as the most likely outcome of a consultation with a GP which young adults wished to avoid and so rarely consulted (Biddle et al. 2006). These findings are in agreement with those of Rickwood and colleagues (2005) who in Australia examined factors that affect help-seeking among young people (aged 14 to 24) for mental health problems. The authors reported that young people tend to believe that seeking professional help does not help (Rickwood et al. 2005).

Similarly, other studies indicated that there may be a reluctance among parents and adolescents (aged 9 to 18) to seek help from services because of a desire to want to solve

problems on their own or because of a belief that the problems will cease without treatment (Abram et al. 2008, Flisher et al. 1997, Pavuluri et al. 1996, Samargia et al. 2006). Moreover, when compared with older adults, young adults with mental health problems have been identified as being more likely to lack the perception that they need treatment (Kessler et al. 2001), and to be more predisposed to thinking that problems would get better by themselves (Kessler et al. 2001).

If negative perceptions regarding formal help-seeking for mental distress prevent many young people from seeking help then the question arises whether many young people recognise the effectiveness of available treatments for mental health problems. This was examined in a recent systematic review of perceived barriers to mental health help-seeking among adolescents and young adults (aged 12 to 25). The review concluded that young people perceived stigma and embarrassment, problems recognising symptoms (poor mental health literacy), and a preference for self-reliance to be the most important barriers to help-seeking (Gulliver et al. 2010). However, a more recent study has provided some encouraging evidence to suggest that attitudes and knowledge about treatment effectiveness and mental illness may no longer be among the main barriers of help-seeking (Eisenberg et al. 2012). Examining untreated college students' reasons for not seeking help for mental health problems Eisenberg and colleagues (2012) in the US reported that for a large proportion of young people with untreated mental illness scepticism about treatment effectiveness was no longer a main barrier. In their study, the majority (65%) of untreated students reported low stigma and positive beliefs about treatment effectiveness, including 42% who perceived a need for help and 23% who did not. The authors therefore recommended that research and practice need to consider new approaches for understanding and influencing help-seeking behaviour (Eisenberg et al. 2012).

Findings regarding the influence of socio-demographic factors on health service use for mental health problems among young people appear mixed. For example, while population-based studies among a broad age group of adults with mental health problems have consistently reported lower rates of mental health service use among employed persons (Bebbington et al. 2000, Bijl and Ravelli 2000, Newman et al. 1996), those with higher education (Bijl and Ravelli 2000, Drapeau et al. 2005, Madianos et al. 1993) and those living on their own (Lefebvre et al. 1998, ten Have et al. 2003) these have not consistently been reported to influence service use among young adults. Biddle and colleagues (2004) and

Vanheusden and colleagues (2008) for example, report that there was no significant association between either occupancy or living arrangements on health service use among young adults with mental health problems (Biddle et al. 2004, Vanheusden et al. 2008). Biddle and colleagues (2004) suggested that this may be because socio-demographic factors such as employment status and living arrangements are more likely to influence service use in middle and later adulthood (Biddle et al. 2004). For example, lone residence may represent a burden among older adults who generally aspire for partnership and may therefore increase their likelihood of help-seeking behaviour. However, young people who live alone are in the middle of the process of becoming independent and commonly require more help from others around them to seek help from services, a combination which may make it difficult to seek help (Biddle et al. 2004).

Studies involving children and adolescents have similarly reported mixed findings regarding the role of predisposing factors such as ethnicity, the socioeconomic status of the family, family composition (such as living in a one parent family), change in family composition, family stress, parents' use of mental health services (Angold et al. 1998, Cohen and Hesselbart 1993, Laitinen-Krispijn et al. 1999, Saunders et al. 1994, Sourander et al. 2001, Verhulst and Der Ende 1997, Zwaanswijk et al. 2003). For example, studies involving children and adolescents that have examined ethnicity appear to be evenly divided between over and under-representation of children from ethnic minorities in services. Such mixed findings are likely to reflect the complex interaction of culture, history, geography and race on health (Angold et al. 2002, Briggs-Gowan et al. 2000, Wu et al. 1999, Zahner and Daskalakis 1997, Zwaanswijk et al. 2003).

To summarise, the literature on health service use for young people with mental health problems has consistently reported that of all the age groups, young adults aged 16 to 24 years are particularly unlikely to seek help for mental health problems. Studies have also indicated a significant interaction between gender and age whereby young adult males appear less likely to use health services for mental health problems while among younger ages girls appear less likely to use health services than boys. The role of socioeconomic status of the family and beliefs on mental health service use appear mixed. It may be that factors such as stigma and perception of problems impact more on service use among young people with specific disorders while have a weaker impact on service use among young people with other

disorders. The next section will review the literature relating to the role of enabling factors on young people's service use.

4.4.3 The role of enabling factors on adolescent and young adult health service use for mental health problems

In addition to predisposing factors, Andersen (1995) argued that enabling factors also influence an individual's use of health services. As described earlier in this chapter, enabling factors are characteristics that act to facilitate or inhibit service-seeking once need is perceived and a person intends to take action. For example, Andersen included resources specific to families (income, savings, and health insurance) and community resources (such as hospital beds, residence and region) (Andersen 1995) as discussed in section 4.3.1.

There is considerable evidence that poor physical health is associated with service contact among young people with mental health problems (Briggs-Gowan et al. 2000, Ford et al. 2008, Gasquet et al. 1999, Zwaanswijk et al. 2003). Although few young people with mental health problems attend health services, those who do appear to do so because of physical rather than mental health reasons (Garralda and Bailey 1986, Giel et al. 1981, Gureje et al. 1994). Given that young adults are generally physically healthy this may act as a barrier to young adults consulting their GP about mental health problems (Patel et al. 2007).

While poor physical health appears to be a strong correlate of service use for mental health problems, the findings regarding the influence of parental psychopathology on service use appear to be more mixed. Some studies have found that parent mental health problems increase the likelihood of children receiving mental health services and that this may be especially true of parents who themselves have received mental health services (Wu et al. 2001). Other research has found, however, that caregiver mental health problems increase the risk that mental health needs will go unmet (Flisher et al. 1997). In particular, parental depression may inhibit help-seeking for children with needs (Barlow et al. 2005). It may be therefore that parental mental health needs increase child mental health needs more than they increase the likelihood of service receipt. Yet, some increase in receipt of children's mental health services may occur if paternal mental health problems trigger services for that parent and these in turn, result in referrals for the child. It is possible that paternal depression influences child service use by reducing parental confidence in parenting and/or by increasing the perceived severity of their child's difficulties (Boyle and Pickles 1997). The level of

perceived parental burden has also been correlated with contact with educational professionals among children with ADHD (Sayal et al. 2006).

Other parent enabling factors that have been reported to correlate with young people's health service use for mental health problems include parent education. As with the role of parental psychopathology, however, the findings appear mixed, with some studies reporting that paternal education has no impact on young people's service use for mental health problems (Owens et al. 2002, Verhulst and Der Ende 1997) and others reporting an association between the lower level of parent education and perceived need for services (Zahner and Daskalakis 1997) or between higher parent levels and service use (Amone-P'Olak et al. 2010). Examining specialist mental health service use among adolescents aged 12 to 15 Amone-P'Olak and colleagues (2010), for example, reported that after controlling for the severity of the child's mental health problems those with mothers who were university educated were three times more likely to consult speciality mental health services (Amone-P'Olak et al. 2010). One explanation for their finding may be that data on parent education was collected from mothers instead of fathers, whereas those studies that have not found an association between parental educational level and service use have collected data on parent education from fathers (who in most cases constituted the parent with the highest level of education) (Verhulst and Der Ende 1997).

It may be therefore that mothers' education is positively associated with mental health literacy, favourable attitudes toward health service use, and less stigma toward mental health problems. This, in turn, may cause enhanced recognition of these problems and facilitate help-seeking. Mothers with higher levels of education may also be more motivated to search for information about mental health problems and may be able to communicate more clearly with health workers about their children's mental health than mothers with low levels of education. In addition, maternal education may be associated with increased reporting of children's mental health problems, and subsequently with increased use of specialist mental health services.

In contrast to the mixed findings regarding the roles of parental psychopathology and parent education in influencing young people's service use, the finding that contact with key adults (such as teachers) can have a powerful influence on service use for young people with mental health disorders appears less inconsistent (Ford et al. 2008, Garralda and Bailey 1988,

Sourander et al. 2001, Sourander et al. 2004, Teagle 2002, Wu et al. 1999, Zahner and Daskalakis 1997). Costello and colleagues (1998) noted that rarely do caregivers act alone in identifying and seeking help for their children but others in the parents' network, such as teachers or friends, may "push" or inhibit families during the help-seeking process (Costello 1998). Indeed, it appears that support from adults in the caregiver's network (e.g. "caregiver network support") may facilitate service use, particularly in cases of severe problems (Thompson et al. 2007). For some parents, however, greater levels of parental network involvement may make treatment seeking more embarrassing (dosReis and Myers 2008).

In addition to caregiver network support, other community resources have also been reported to correlate with health service use for young people with mental health problems. In countries where healthcare is not readily available to everyone, financial constraints are likely to influence service use, and socioeconomic factors are likely to influence professional help-seeking. However this is not likely to be the case in countries like the UK where the national healthcare system is free for all (Gasquet et al. 1997, Sourander et al. 2001, Verhulst and Der Ende 1997, Zwaanswijk et al. 2003). However, studies that have reported significant findings have been fairly evenly split between reports of more service use among advantaged or disadvantaged groups. This may partly be explained by families of different socioeconomic status tending to use different settings, such as middle class families opting for education-based services (Gasquet et al. 1999, Kumpulainen et al. 2001, Laitinen-Krispijn et al. 1999, Zahner and Daskalakis 1997).

As the majority of the studies investigating the factors influencing help-seeking have been conducted in the US it is questionable whether similar factors would influence the help seeking behaviours of parents in the UK. Subtle differences are noticed in the way in which parents in these countries access help from child mental health services. In the UK specialist child services such as CAMHS, are accessed following a referral from the child's GP, whilst in the US these services are accessed directly from private health insurance, with the paediatrician being the first professional parents will meet (Sayal 2006). The complex pathway to specialist services in the UK, and the long waiting lists involved, may deter parents from seeking help from their GP, or from continuing to wait to receive help from CAMHS (Sayal 2006). However, even within countries the region in which one lives may also significantly impact on the quality of service provision one is likely to receive (Ford et al. 2008, Sturm et al. 2003).

To summarise so far, while there is strong evidence to suggest that young people with physical health problems are more likely to use services for mental health problems and that health service use for mental health problems among young people is associated with important adults as well as the parental social network, socio-economic factors appear to play a lesser role on health service use in countries such as the UK where the healthcare system is free for all. The impact of parental education and parental psychopathology appears mixed as does the role of the geographical region in which young people reside. It is likely that inconsistencies in study findings reflect differences in study methodologies (for example, differences in choice of sample, age, types of services included, nature of predictors examined) as well as statistical approach (Sayal and Ford 2010).

4.4.4 The role of need factors on adolescent and young adult health service use for mental health problems

One of the most consistent findings of studies that have looked into health service use for young people with mental health problems is that, as expected, the presence and severity of psychopathology is highly predictive of service use for mental health problems across all services (Aalto-Setälä et al. 2002, Briggs-Gowan et al. 2000, Ford et al. 2008, Kessler et al. 1999, Koot and Verhulst 1992, Merikangas et al. 2011, Wittchen et al. 1998, Zwaanswijk et al. 2003). In particular, parental recognition of the young person's symptoms or impairment, is generally reported to be a strong correlate of children's and adolescents' health service use (Flisher et al. 1997, Pavuluri et al. 1996, Rickwood et al. 2007, Wu et al. 1999). Parental recognition of their child's symptoms or impairment can be difficult to disentangle from the objective presence of symptoms and psychopathology as the presence of symptoms or impairment is often established, at least partially if not entirely, from parental accounts. Indeed, for children and young adolescents especially, parents are the main informants in endorsing whether symptoms are present and in determining the type and severity of a possible disorder (Sayal and Ford 2010).

Among children with mental health problems, parental recognition that their child's symptoms or impairments are causing problems has also been identified as a key step in the help-seeking process (Owens et al. 2002, Sayal 2006, Sayal et al. 2006). The findings are more mixed in studies involving adolescents and young adults (Klineberg et al. 2011, Zwaanswijk et al. 2003). Zwaanswijk and colleagues in the Netherlands, for example, who

examined mental health service need and utilisation in a sample of adolescents in the general population found that adolescents' subjective need for help did not necessarily lead to help-seeking actions (Zwaanswijk et al. 2003). The authors noted that adolescents who recognise the problematic nature of their behaviour and feelings may be less likely than parents to translate their concern into help-seeking actions, and may be less able to initiate single-handedly mental health service use (Zwaanswijk et al. 2003). However, it is important to note that even among children with mental health problems the degree of psychopathology is not always a determinant of health service use. Some studies have found that parents may recognise the persistent nature of their child's symptoms and impairments but perceive that they should be able to deal with these problems themselves (Douma et al. 2006, Pavuluri et al. 1996). Therefore, the presence and severity of psychopathology along with problem-recognition may only partially explain why young people and families use services for mental health problems.

Another essential finding of studies that have examined correlates of health service use among young people with mental health problems is that the type of symptom or psychopathology may also impact on whether or not a service is used. For example, studies involving parents of children and adolescents with mental health problems have found that parents are more likely to regard disruptive rather than internalizing disorders as burdensome (Angold et al. 1998) and are subsequently more likely to seek help from mental health services (Anderson et al. 1987, Sourander et al. 2001, Verhulst and van der Ende 1997, Zwaanswijk et al. 2003, Wu et al. 1999). However, other studies, mainly involving older adolescents or young adults, have found that it is internalizing symptoms rather than externalizing (or disruptive) symptoms that are linked to health service use (Sourander et al. 2004). Sourander and colleagues (2004), who conducted a prospective study of mental health service use in 18 year-olds in Finland found that anxious-depressive and withdrawal symptoms (e.g. internalising symptoms) were the most strongly associated factors with health service use among all the psychopathology variables. They suggested that one possible reason for these mixed findings may be that when adolescent self-reports rather than parental reports are used (as they were in their study) internalizing symptoms are more likely to be picked up as adolescents may be more reliable informants on internalizing problems than parents. It is a shame that the study did not include both self and parent reports to test this theory. In addition, Sourander and colleagues (2004) also noted that the difference in findings

may result from the fact that an older sample (e.g. only 18 year olds) were used in their study compared with the younger sample used in the study by Zwaanswijk and colleagues (2003) (e.g. 11 to 18 year olds). The authors noted that in their previous study (Sourander et al. 2001), which also found a significant association between externalizing problems and health service use, a younger sample of 8 to 16 year olds was used as well (Sourander et al, 2001).

In summary, the presence and severity of psychopathology has generally been reported to correlate with health service use among young people with mental health problems. Adolescents and young adults may be more reliable informants than parents on mental health problems, especially internalising symptoms such as depression, which may help to explain why a difference can be seen among children and adolescents in studies examining the effect of type of symptom on health service use. Moreover, it appears that factors such as parental and young people's perceptions regarding symptoms and impairments are important to understanding health service use for mental health problems among young people. However, how parents and young people interpret their child's symptoms and behaviour and their level of concern may also reflect socio-demographic factors and the next section will shift to review the role of predisposing factors on adolescents' and young adults' health service use for ADHD.

4.5 Correlates of health service use among young people with ADHD: a review of the literature

As discussed in Chapter 3, previous studies have identified that there is an almost complete disengagement from health services among young people with ADHD by the age of 21 (McCarthy et al 2009). This is likely to be due, in part, to symptom reduction by the time young people with ADHD reach adulthood. However, it is unlikely that an almost complete disengagement from health services can be solely explained by symptom remission. As discussed in Chapter 2, around two thirds of ADHD children will continue to suffer from impairment as a result of symptoms at age 25 (Faraone et al. 2006). Disengagement from services may to some degree reflect a conscious decision by young people to opt out of treatment. Nevertheless it is likely that other factors are also important as contributing factors to declines in service use. An improved understanding of the factors associated with health service use among young people with a childhood diagnosis of ADHD is of vital importance given the long-term risks associated with persisting ADHD.

Most of the literature on service use among individuals with ADHD has been carried out in the US and has focused on children (Bussing et al. 1998, Bussing et al. 2003b, Eiraldi et al. 2006, Leslie and Wolraich 2007). These studies have indicated that individual, caregiver and system-level factors are associated with the use of services in this group (Eiraldi et al. 2006, Leslie and Wolraich 2007). The role of predisposing characteristics such as ethnicity and gender on health service use has been highlighted by most of these studies. For example, children in the US with ADHD from racial and ethnic minority backgrounds as well as girls are less likely to receive stimulant medication treatment compared with similar groups from Caucasian backgrounds and to boys (Bussing et al. 2003b, Eiraldi et al. 2006, Leslie and Wolraich 2007). Studies by Eiraldi and colleagues (2006) and Leslie & Wolraich (2007) also discovered that children with the disorder in the US who were enrolled in publicly funded health insurance plans were less likely to use health services than the privately insured. The role of insurance and other socio-economic factors on influencing health service use is not likely to be significant in countries such as the UK where the access to the healthcare system is open to all.

Another essential finding in US and British studies is the importance of considering both parent and individual characteristics as correlates of service use in children with ADHD (Angold et al. 1998, Sayal et al. 2006). As parents and teachers are often the first people to suggest that a child be assessed and treated for ADHD they have come to be perceived as "gate-keepers" for accessing specialist mental health services for the diagnosis and treatment of ADHD (Sayal et al. 2002). Using the 2004 British Child and Adolescent Mental Health Survey to examine correlates of service use among 5 to 16 year olds with ADHD, Sayal and colleagues found that although comorbid emotional or behavioural disorder predicted contact with education based professionals, contact with primary and specialist health services was predicted by severity of ADHD and parental burden (Sayal et al, 2010). The authors noted that when compared to their earlier study (Sayal et al, 2006) which found that predictors of service use mainly reflected parental factors, such as parental recognition of problems and perceived burden, the influence of child-related factors on children receiving services appears to have grown (Sayal et al, 2010).

Parents of children with ADHD who perceive their child's behaviour as problematic have also consistently been shown to be more likely to seek help and use health services (Sayal 2006, Sayal et al, 2002; Sayal et al, 2003). For example, in a study using a pathways to care

model for children with pervasive hyperactivity, Sayal (2006) identified parental perception that hyperactivity was a problem as the most powerful barrier to contact with primary care for any reason (Sayal 2006). However, in a recent study by Bussing and colleagues (2011), which assessed adolescents, in contrast to children, with ADHD, parental ratings of inattention (but not of hyperactivity/impulsivity, ODD or CD) were associated with mental health service use. One explanation for this may be that attentional capabilities play an increasingly important role during adolescence, when school assignments become more complex and inattentive ADHD symptoms result in notable performance problems. While inattention, hyperactivity/impulsivity, ODD and CD may all be problematic among adolescents, inattentive behaviours may be interpreted as a clear signal that help is needed whereas ODD and CD may be viewed as typical adolescent misbehaviour and one which does not prompt help-seeking from a professional (Bussing et al. 2011).

However, given that no studies have investigated the role of conduct disorder on health service use among young adults with ADHD (only adolescents were interviewed in the study by Bussing and colleagues (2011)), it remains unclear if a similar argument can also be applied to this age group. As studies have indicated that early conduct disorder may significantly increase the likelihood of poor outcomes among adolescents and adults with ADHD (Babinski et al. 1999), it may be that having received a diagnosis of conduct disorder in childhood significantly increases the likelihood of contact with health service use among young adults with ADHD.

As in the literature review on correlates of health service use among young people with mental health problems, a significant gap has also been identified between problem-recognition and seeking help among those with ADHD. Bussing and colleagues (2003) found that although the vast majority of parents (88%) in their sample recognised that their child had a problem, only a third of these children (39%) had been assessed for ADHD. Over two thirds of parents did not see a need for professional treatment even though their child fulfilled the criteria for ADHD (Bussing et al. 2003c). Bussing and colleagues (Bussing et al. 2003c) hypothesised that this discrepancy may be due to parent's lack of knowledge about the nature and course of ADHD, for example not considering ADHD to be a medical condition. However, these factors were not assessed in their study. Similar results have also been found in a UK study, in which most parents (80%) recognised their child to have a problem but only just over a third (35%) labelled this as hyperactivity and sought professional help (Sayal and

Taylor 2005). Deficits in knowledge about ADHD have been linked to a variety of factors: parenting stress (Mash and Johnston 1983), reduced problem recognition (Bussing et al. 2003a), and parental enrolment and engagement in treatment (Johnston et al. 2005, McNeal et al. 2000). In a recent mixed methods study examining perceptions related to ADHD treatments (pharmacological and psychosocial) from both parent and adolescent perspectives knowledge of ADHD treatments was found to be a significant correlate of willingness to engage in treatments for ADHD indicating that deficits specifically related to ADHD treatments are important in determining contact with services (Bussing et al, 2012).

Reluctance to seek help when recognising problems may be therefore be the result of insufficient knowledge about ADHD treatments but may also result from concern about, or even fear of, drug treatments. In addition, stigma about both mental health problems and health services is likely to be a major reason for parents not reporting concerns. This can result in parental shame and guilt (Costello et al. 1993), anxiety, and denial of mental health problems. Attitudes of referrers, teachers and the media can perpetuate the stigmatization of mental health issues. In particular, parents may be concerned that they will be regarded as a failure or blamed for their child's difficulties. The above perceptions may reflect limited or inaccurate knowledge about health services or ADHD.

Indeed, substantial ADHD stigma concerns among adolescents have been identified as having a significant impact on health service use (Bussing et al. 2011, Walker et al. 2008). Bussing and colleagues who examined parent and adolescent perspectives on clinical need for and attitudes toward care for ADHD using data from a longitudinal cohort study reported that adolescent ADHD stigma perceptions, along with parent and adolescent-reported need (symptom and functioning respectively), contributed significantly to past year use of mental health services above and beyond parent perspectives. Bussing and colleagues hypothesized that such stigma and perception may impede help-seeking or promote discontinuation of treatment because adolescents are developmentally sensitive about public opinions and seek peer approval (Bussing et al. 2011).

When it comes to caregiver factors that are related to health service use, several studies have documented that high levels of caregiver burden are associated with ADHD (Angold et al. 1998, Bussing et al. 2003a, Podolski and Nigg 2001). Previous literature suggests that among young people with ADHD, particularly those under 18, parents are likely to be the primary

decision-makers, with respect to seeking, obtaining and continuing use of services. Although separation and individuation are likely to be primary developmental goals for adolescent and young adults with ADHD, it is also likely that the attention and assistance of adults to facilitate the complex process of seeking and obtaining such services is frequently required (Zwaanswijk et al. 2003). Carer burden may increase or decrease the likelihood of parents encouraging their children in seeking out services.

Previous research suggests that burden of the parent and functional impairment of the child, rather than symptom severity, are the best predictors of health service use in children with ADHD (Angold et al. 1998, Leaf et al. 1996). Angold and colleagues (1998) who examined the level of burden experienced by parents of young people with mental health problems (including ADHD) found that parental burden was associated with both the number of symptoms and impairments as well as parental psychopathology, while the effect of the severity of the child's disorder on health service contact was mostly mediated by parental burden (Angold et al, 1998).

An association between lower levels of parental social network support and seeking ADHD treatment has also been reported (Bussing et al. 2003c). Bussing and colleagues (1998b) who examined health service use for children with symptoms of hyperactivity using Andersen's (1995) and Screebnik's and colleagues (1996) help-seeking models, found that although predisposing factors (such as male gender and Caucasian ethnicity) rather than need factors were generally associated with health service use, use of specialist mental health services in the previous year was associated with parental burden as well as conduct problems. Parental factors such as parent mental illness or distress are known to correlate with medical care, particularly in studies involving young children (Tessler and Mechanic 1978). In addition, a relationship between the lower educational level of the mother and the higher use of health services by the child with ADHD has also been reported (Bruijnzeels et al. 1995, Zahner and Daskalakis 1997).

In summary, individual, caregiver and system-level factors all appear to be associated with health service use among children and adolescents with ADHD. US studies have consistently reported that ethnicity, gender and health insurance have a significant impact on health service use among children with ADHD; however as these studies are not UK based they may not reflect the factors influencing help-seeking and health service use among young

people and their parents in the UK. Studies have generally reported that caregiver burden and the parental perceptions of hyperactivity as a problem have a significant influence on service use although findings should be interpreted with caution due to the variety of different methodologies and participants used, for example questionnaires, interviews and parent recall of parents of children either “at risk” of ADHD or diagnosed as “hyperactive”. In addition, the role of inattentive symptoms should also be considered as both inattentive and hyperactive symptoms may be important in influencing service use among adolescents and young adults with ADHD. While some studies have indicated that age may be an important factor in influencing service use among this group, no studies to date have examined the relative contribution of age alongside a range of enabling and need factors on health service use in adolescent and young adults with a childhood diagnosis of ADHD. The present study sought to address this gap in the literature.

4.6 Outline of factors chosen for this study

Need factors chosen in this study comprised ADHD symptoms (inattentive and hyperactive/impulsive), comorbidities (neurotic symptoms), impairments in daily living, needs (as assessed using the CANDID), childhood diagnosis of conduct disorder and parent carer burden. As discussed in the previous sections, studies among children with mental health problems have consistently reported that the presence and severity of psychopathology is associated with health service use, however it is unclear whether or not ADHD symptoms, neurotic symptoms, impairments, needs, a childhood diagnosis of conduct disorder or parent carer burden are associated with service use among 14 to 21 year olds with a childhood diagnosis of ADHD. Theoretically, both inattentive and hyperactive/impulsive symptoms may increase the likelihood of seeking help. However, ADHD is also highly associated with comorbidities (e.g. depression and anxiety) and impairments which may be significantly associated with service use in this group. In addition, having a large number of needs may also increase the likelihood of using health services. Further, given that studies have indicated that early conduct disorder may significantly increase the likelihood of poor outcomes among adolescents and adults with ADHD (Babinski et al. 1999), it may also be the case that having received a childhood diagnosis of conduct disorder may increase the likelihood of being in contact with health services at follow-up. Lastly, high levels of carer burden may also be associated with service use in this group given the strong link between caregiver burden and

health service use among children with ADHD reported in previous studies (Angold et al. 1998, Bussing et al. 2003a, Podolski and Nigg 2001).

This study chose to examine the young person's age as a potential predisposing correlate of health service use. As discussed in previous chapters, considerable barriers to health service use currently exist for those with a childhood diagnosis of ADHD leaving child and adolescent services. Few services currently exist for adults with ADHD and there may be particular problems at transition from child to adult health services for those with neurodevelopmental disorders (Singh et al. 2010b). In addition, as seen in the literature review on service use among people with mental health problems in general, only 25% of those between the ages of 16 to 24 years who were identified as having a mental health disorder seek and use mental health services (Aalto-Setälä et al. 2002, Bergeron et al. 2005, Kessler et al. 2005, Newman et al. 1996, Patel et al. 2007, Rickwood and Braithwaite 1994, Vanheusden et al. 2008). Many drop out of services after leaving paediatric or child and adolescent services although the reasons for this are not clear. It was therefore hypothesised that age would be an important predisposing correlate of health service use in the current study.

Although other predisposing factors (e.g. gender and ethnicity) have been shown to be important correlates of service use among young people with ADHD (Bussing et al. 2003c, Eiraldi et al. 2006, Leslie and Wolraich 2007) this study was unable to examine the effects of gender and ethnicity due to the small number of girls in this study and given that all participants were of Caucasian background.

Enabling factors comprised parent level of education, family geographical residence and information about ADHD. Wide geographical variation in the treatment of ADHD has been reported, especially in adults (National Institute for Clinical Excellence 2008). Given that London and regions near to London have some of the few available national services for adults with ADHD it was hypothesised that families living in Greater London may have easier access to these services than families living outside Greater London resulting in higher reporting of service use among this group. Studies looking at adolescent mental health service use in general have found that residents of urban areas seek services more frequently than those from non-urban areas (Cohen and Hesselbart 1993). It was also hypothesised that those reporting no needs in information about ADHD (assessed using the CANDID) would have

sufficient knowledge about the nature and persistence of ADHD in adulthood which would result in higher reporting of health service use among this group. Lastly, given that parent level of education, especially that of the mother, has been reported to be an influential factor in mental health service use among young people, the role of parent education was also chosen as a potential correlate of health service use. Better educated parents may make more contacts with mental health services for their child (Drapeau et al. 2005, Gavrilovic et al. 2005) although studies have also reported an association between lower educational level of the mother and higher use of health services among children with ADHD (Bruijnzeels et al. 1995, Zahner and Daskalakis 1997). It remains unclear what role parent education plays in health service use among adolescents and young adults with ADHD.

The next chapter describes the methodology of this study, beginning with a brief reminder of the aims and objectives of this study.

CHAPTER 5

Methods

5.1 Background

A key aim of this study was to investigate needs and service use among those diagnosed with ADHD at transition from adolescence to young adulthood (14 to 21). Although ADHD is a developmental disorder which is known to often persist into adulthood, little is known about needs and service use in this group, especially at the transition to adulthood. ADHD is an important clinical group as treatment and management are known to exist but there is evidence to suggest that those in this group are currently under-treated. Moreover, ADHD is frequently associated with a range of psychiatric comorbid disorders such as antisocial behaviour, anxiety and depression, all of which are likely to increase the need for services and interventions.

In particular, this study sought to investigate health service use of young people with ADHD in the context of associated health and demographic factors and aimed to examine how well services and families are currently meeting the needs of these young people. It further sought to explore the experience of healthcare transition (transfer and process) among this group in terms of both the transfer to adult health services and the processes involved in preparing families for this transition.

This study formed part of a wider 5 year programme funded by the National Institute for Health Research (NIHR) ('Crossing the divide: Effective treatments for people with neurodevelopmental disorders across the lifespan and intellectual ability') that aims to develop more effective services and treatments for adolescents and young adults diagnosed with ADHD. The long term goal of this and the wider study is to inform and further the debate within public policy as to how care programmes may be devised and implemented for this group in order to offer appropriate care for young people with ADHD at transition from child to adult health services.

5.2 Research questions

The specific research questions addressed by this study were:

- (i) What are the met and unmet needs among those with a childhood diagnosis of ADHD at transition from adolescence to young adulthood (aged 14 to 21 years) and to what extent are services and family members/friends meeting the needs of this group;
- (ii) What predisposing, enabling and need factors are associated with health service use (and mental health service use in particular) among adolescents and young adults at transition from adolescence to young adulthood (14 to 21) who received a diagnosis of ADHD in childhood;
- (iii) How do young people with a childhood diagnosis of ADHD and their parents experience healthcare transition (i.e. the transfer and processes) during the transitional years from adolescence to young adulthood.

5.3 Study design

This was an observational study using face-to-face structured interviews and self-completion questionnaires with young people with ADHD and their parents or partners (usually mothers). This study used the baseline (first year) data of a 3 year prospective study that formed part of the wider 5 year programme funded by the NIHR (described in sections 1.3 and 5.1). It examined the use of health services and assessed current health and social needs of this clinical group. The study further collected social, demographic and health information relating to the participants and the participant's family member at the time of the interview. The face-to-face interviews were conducted at the young person's family home (or at the Institute of Psychiatry if preferred by the participants, with travel expenses reimbursed) and involved separate interviews with the young person and the parent to ensure confidentiality during the interview process. A self-completion questionnaire was also administered to the adolescents/young adults after the completion of the young person's interview to obtain information regarding drug and alcohol use and problems with police in order to ensure confidentiality of the responses, while at the same time enabling the researcher to check that questionnaires had been filled in correctly. The self-completion questionnaire was fully read out to three participants who reported having problems reading or writing. Parental interviews obtained information about the child's behaviour and needs from the parents'

perspective but also enquired about the parents' own social and demographic background and their general health and wellbeing (including carer burden). Following these two separate interviews, a final joint interview was carried out with the young person and their parent to assess health service use and experiences of healthcare transition. Moreover, a diagnostic measure of ADHD was also administered. This approach to collecting information was based on the knowledge that some questions were best answered privately due to their sensitive nature, and that some required a face-to-face format. The details of this study will be described below.

5.3.1 Study site

Data collection took place in participant's homes unless a different location was preferred. Most participants found this to be the most convenient location for them; however, four families preferred to be interviewed at other locations, including one family who wished to be interviewed at a relatives' house as they lacked the space for two separate interviews in their own home. Another family wanted to be interviewed in a coffee shop near their home. Two further families chose to be interviewed at the main study site (Institute of Psychiatry, King's College London) as they felt that this would be a more comfortable environment for them.

While around half of the participants lived in Greater London, the remainder were spread throughout England from Cornwall to Lincolnshire in the North East.

5.4 The sample

5.4.1 The IMAGE study

This study was based on an existing clinical research sample used in the International Multi-Centre ADHD Genetics (IMAGE) Project. IMAGE was a genetic study of ADHD (sample size=204) carried out by researchers at the Institute of Psychiatry between June 2003 and January 2006 (on average 4.8 years (sd. 0.9) prior to the follow-up assessments). The IMAGE study formed part of a wider European collaborative genetic study of ADHD (with a full sample size of around 1400) (Kuntsi et al. 2006). Families in the IMAGE study were recruited by referral from child and adolescent clinics in the southeast of England on the basis that they had received a clinical diagnosis of combined type ADHD (as defined in the DSM-IV manual) and had at least one surviving biological sibling. This restriction on the combined

subtype was chosen due to the genetic focus of the IMAGE project (Asherson 2004). Both participants and their siblings (at the time of recruitment) were included in the IMAGE study if they were between the ages of 5 to 17, had an IQ of 70 or higher, were of European or Caucasian descent, and had at least one biological parent willing to provide DNA samples. At the time of assessment for the IMAGE study, the mean age of participants was 12.2 years (sd. 2.3).

Participants were excluded from the IMAGE study if they (or their siblings) had been diagnosed with: autism, epilepsy, general learning difficulties, brain disorders, and any genetic or medical disorder associated with externalising behaviours that might mimic ADHD based on both history and clinical assessment. Children with classical or atypical autism were excluded from the IMAGE project because some genetic regions are known to be associated both with autism and ADHD (Asherson 2004).

5.4.2 Sample selection

An investigation of the IMAGE research database showed that 154 out of the 204 young people in the original sample were between the ages of 14 and 24 by the 1st of March 2009. This age range was chosen as it was felt it was the most appropriate for the purposes of the study reported here: an investigation focusing on needs and service use in a group who had either recently undergone (or were currently undergoing /about to undergo) the transition from child to adult health services. The current needs and service use of these young people were unknown at the time of the study; therefore, the focus was to collect information about the young person's needs and services use as well as the parents' role in their child's transition between child and adult services. Consequently, the original IMAGE sample was followed up in order to examine the needs and service use of this group during the transition from childhood to adulthood.

5.5 Recruitment approach

5.5.1 Invitation letters

All participants aged 14 to 24 in the IMAGE research database were invited by the author to participate in the study. Parents and young people were each sent separate letters of invitation and information sheets (see Appendix B) explaining the study together with an update form

and a stamped addressed envelope for return to state their interest in the study. The author's contact details along with those of two of the main investigators of the larger NIHR project, Professor Philip Asherson and Dr Karen Glaser (Professor Asherson was also the lead researcher for the IMAGE study) were included in the letters for those who wished to receive more information about the study (see Appendix B for all recruitment documentation).

Invitation letters and information sheets explained (i) the rationale of the study; (ii) what the study would involve (i.e., a face-to-face interview lasting about 2 hours including the completion of a self-completion questionnaire and a joint interview with the both parent and young person) assessing needs, health service use and healthcare transition and (iii) the confidential aspects of the study (i.e., that the young person and parent would remain blind to each other's responses given during their individual interviews with the interviews being carried out in two separate rooms; participants would be identified by a number and not their names; data gathered would remain confidential solely to be used for research purposes and would not be shared with anyone apart from those directly involved in the research study).

Parents were asked to return an update form indicating whether or not they were interested in taking part in the study. An opt-out alternative was given, whereby parents could indicate that they did not wish to be contacted to discuss the study any further.

In addition, the update form also asked the parents to give up-to-date information about further contact details and to indicate preferred ways of contacting them. Moreover, information about their children's diagnoses and medication use was also collected on the form (see "Update form" in Appendix B).

5.5.2 Responses to invitation to participate

Recruitment began in March 2009 and continued until 92 eligible families had been recruited in December 2010. A total of 154 invitation packs were sent out between March 2009 and March 2010 to eligible families with a young person in the 14 to 24 age range by March 2009. Of these, 24 families (16%) returned the update form indicating interest (n=9) or disinterest (n=15) in participating. Those who indicated interest were contacted via phone within two days of receiving the update form. Where update forms were not returned (n=130), contact with families was attempted via telephone within 10 days of sending the invitation pack.

Out of the 154 families invited to participate, 23 families could not be contacted despite persistent attempts to obtain additional contact details for the families (e.g. by researching old files and by attempting to contact a relative who between 2003 and 2006 had been given as an additional contact). Of those who could be contacted (n=131), 34 families refused to participate, 97 families accepted to participate; however, of these 5 families continuously postponed the interview and in the end could not be interviewed within the timeframe of the study, resulting in 92 families who ended up participating (ten of these families were subsequently removed from the final analyses, as explained in section 5.8.2). The reasons for refusals and other details of recruitment are shown in Table 5.1.

Table 5.1 Distribution of responses to invitation to participate in study (column %)

| Response to study invitation | n (%) |
|---|--------------|
| Uncontactable (despite persistent attempts) | 23 (15) |
| Accepted (took part) | 92 (60) |
| Accepted (but never took part) | 5 (3) |
| Refused, of which: | 34 (22) |
| <i>too busy</i> | 8 (5) |
| <i>family conflicts</i> | 10 (7) |
| <i>health reasons</i> | 7 (4) |
| <i>not interested</i> | 9 (6) |
| Total invitations sent out | 154 (100) |

5.5.3 Telephone recruitment

When initial telephone contact was made with the families, the researcher first thanked the parents for sending back the update form and showing interest in the study (or in cases where update forms had not been received, for taking part in the previous IMAGE study). An attempt was made to gauge if the parents had read the information sheet and understood what the study was about. Where parents stated that they had not read the information sheet, a brief summary of the rationale of the study was given, followed by an explanation of what the study would involve including the confidential aspects of the study (see Appendix B for information given in invitation letters).

In order to persuade families to participate, the researcher emphasized the confidential aspects of the study as well as the informal nature of the interview process, informing the parents that participation would not involve any tests and that no right or wrong answers would be expected of participants. The researcher also emphasized that despite the two hours that would need to be put aside towards the interviews, participants would be free to have breaks and to ask questions at any time. If necessary, the researcher also distinguished the study from the previous IMAGE studies they may have participated in, explaining that no swabs or blood tests would be necessary for this study. The importance of using two separate rooms to ensure the confidentiality of the parent and the young person during the interviews, and the benefits of carrying out these two interviews at the same time, were also emphasized by the researcher.

If families consented verbally to taking part, an attempt was made to arrange a suitable time and date to interview. The families were asked when would be a good time for them to do the interviews and where they would prefer to do them. It was felt important to accommodate the families as far as possible by ensuring that the time and place of the interviews were convenient for them and by being flexible in cases where they wished to re-arrange these appointments.

In cases where the families refused to participate, the families were gently asked to give a reason for this (e.g. if not given voluntarily) and asked if they would be interested in participating at a later date. Wherever possible, an attempt was made to reinforce the benefits of taking part in the study and to inform the families of its flexible and informal nature, (this did convince some families to take part). If families still did not wish to participate at a later date no further contact with the families was made.

In instances where families had omitted information requested on the update forms, or where families agreed to participate but had not returned the update forms, the researcher also made an attempt to ask parents for this information (or to clarify information given on the update form, such as their address, telephone numbers, child's diagnosis and medication use).

Participant recruitment is displayed in the flow diagram in Figure 5.1.

5.5.4 Obtaining consent

Obtaining consent involved two stages: (i) verbal consent over the phone or email and (ii) written consent on the day of the interview. Written consent consisted of both parental and child consent. Those adolescents and young adults aged over 16 years could give sole informed consent whilst younger participants required both personal and parental consent. The consent forms are included in Appendix C.

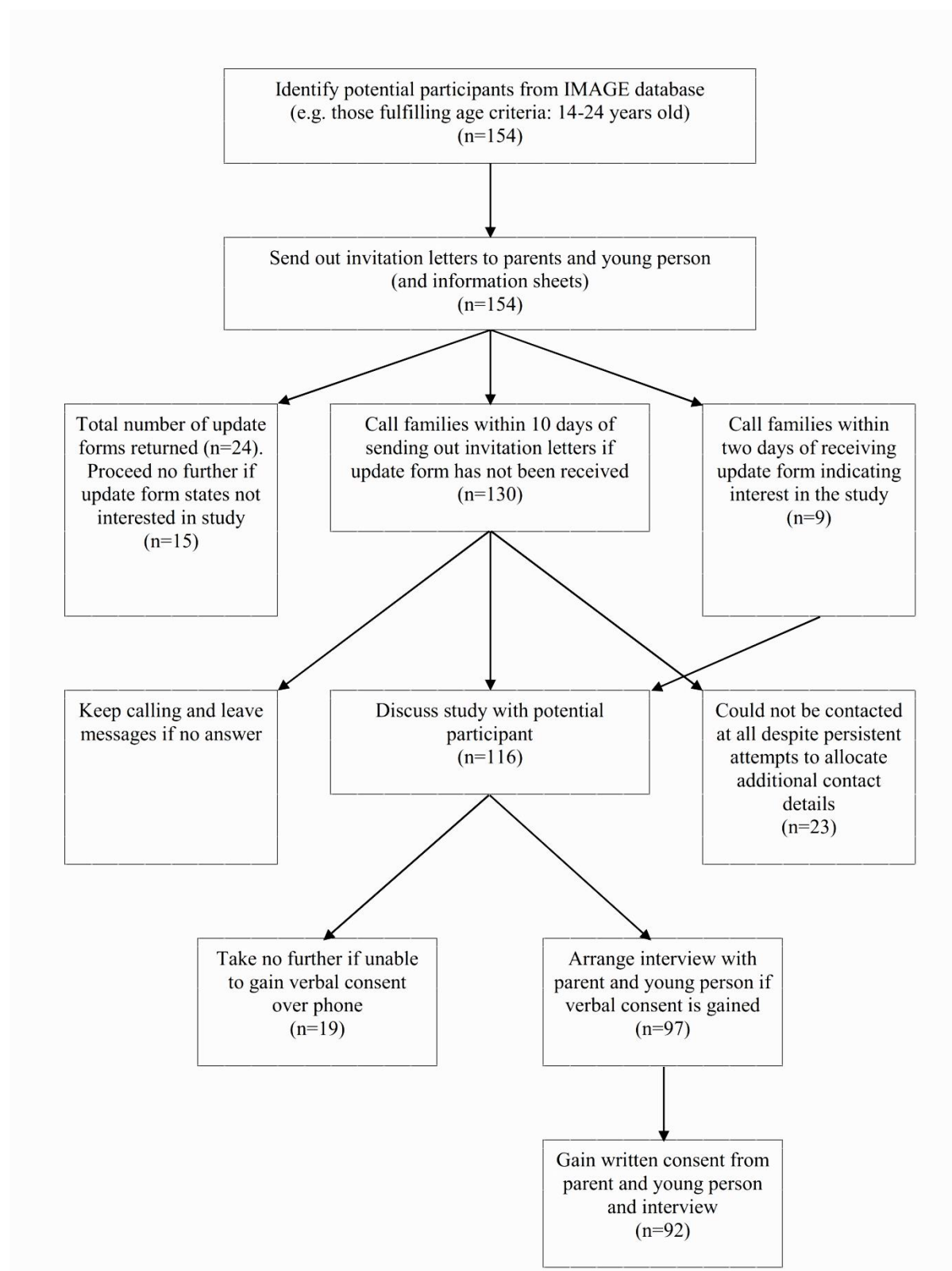


Figure 5.1 Participant recruitment procedure

5.5.5 Characteristics of refusals

To estimate characteristics of refusals information regarding participants' gender, age, childhood family economic status, and childhood ADHD symptoms (the latter two taken from the earlier IMAGE research database) were used to compare those who accepted and refused to participate. Unfortunately, no participants in the age range 22 to 24 years wanted to participate in the study (out of a possible four participants in this age range). One of the reasons given for this refusal was that the young person was no longer living at home and would not have the time to participate in research. In addition, two mothers reported that they were no longer on speaking terms with their child. However, as can be seen in Table 5.2 there was no significant difference in response rates by gender or by mean age (0.7 years) between refusals and acceptors. There was, however, a statistically significant difference in the mean childhood inattentive symptom score between the two groups with the acceptors reporting a higher inattentive symptom score ($t= 2.311$, $df. 108$, $p= .02$). Even so, the small effect size (the difference between the two means divided by the common standard deviation) suggests that this is not likely to be meaningful.

Table 5.2 Characteristics of participants who accepted to take part in study

| Variable | Acceptors (n= 92) | Refusals (n=62) | p-value |
|---|----------------------|--------------------|-----------------------------|
| Gender (female) | 9 (11) | 2 (6) | $p= .73$ |
| Age (years) | 17.5 (2.3) | 18.2 (2.5) | $p= .60$ |
| Childhood socio-economic status score | 4.08 (1.0) | 4.14 (1.7) | $p= .80$ |
| Childhood inattentive symptom score | 22.6 (3.7) | 20.6 (5.0) | $p= .02$, effect size= .46 |
| Childhood hyperactive/impulsive symptom score | 19.1 (5.6) | 19.3 (5.9) | $p= .59$ |
| Childhood combined symptom score | 41.4 (8.8) | 39.9 (10.1) | $p= .45$ |

Note: Mean (sd.) or numbers (%), Childhood variables (i.e. socio-economic score (SES), inattentive symptom score, hyperactive/impulsive symptom score, and combined symptom score) were accessed from the IMAGE research database (see 5.7.4 for details).

5.6 Instruments

5.6.1 Outline of study instruments

The instruments for this study were administered in the format of three separate face-to-face interviews and one self-completion questionnaire. The young people's questionnaire booklet was carried out as a face-to-face interview and consisted of: (i) background information (e.g. marital status, living arrangements, current daily activity, school (or work) functioning and disability days as part of the CSRI); (ii) a needs assessment based on the CANDID (i.e. a standardised needs-assessment instrument that assesses need in 25 life domains, described in more detail below); and (iii) the Clinical Interview Schedule-Revised (CIS-R) (that is, a rating scale of comorbid psychological symptoms).

Following the completion of the face-to-face interview, young people were also asked to complete a self-completion questionnaire consisting of: (i) the Barkley ADHD rating scale for adults (i.e., questions about attention and activity levels over the last 6-months, a reliable and valid measure of behaviours that are common in ADHD and which is described in more detail below); (ii) the Center for Neurologic Study- Liability Scale (CNS-LS), a mood liability questionnaire; (iii) the Alcohol Use Disorders Identification Test- Consumption Questions (AUDIT-C), an abbreviated version of a widely used self-reported measure of alcohol; (iv) a brief series of questions on drugs adapted from the ONS Survey of Child and Adolescent Psychiatric Morbidity and, finally; (v) a brief series of questions about police contact (e.g. custodial sentences, times spent in a prison cell, court).

In contrast to the young person's questionnaire booklets, the parents' questionnaire booklet was carried out entirely face-to-face and consisted of: (i) background information (e.g. marital and tenure status, living arrangements as part of the CSRI); (ii) completing the same questions about their son/daughter's attention and activity levels using the Barkley ADHD rating scale for adults and the same questions about the young person's needs (using the CANDID) as completed by the young person (this is because it is sometimes difficult for young people to judge their own levels of attention and needs so it may be beneficial to ask someone who knows the young person well (usually parent or partner) to complete some of the same questions about the young person); (iii) questions about the frequency and type of services used by the parent/partner, using an adapted version of the CSRI; (iv) questions assessing the impact of their son/daughter/partner's condition on their own employment

situation (part of the CSRI); (v) the Short Form-12 general health questionnaire (SF-12), that is, a measure of the parents' or partners' physical, psychological and social wellbeing; and (vi) the Zarit Carer Burden Interview (the abbreviated version), a widely used measure of carer burden.

Finally, the young person and parent face-to face joint interview booklet consisted of: (i) the Diagnostic Interview for ADHD in adults (the DIVA described in more detail below), and (ii) the CSRI, adapted for this clinical group, asking information about the adolescent/young adult's frequency and type of service use in the last three months and contact with transition teams and services. Table 5.3 summarises the content of the interviews.

Table 5.3 Summary of interview content

| Interview content |
|--|
| Young person interview: face-to-face measures |
| Background information (Current employment, schooling- CSRI (Beecham, 2009) |
| Needs assessment, CANDID (Xenitidis et al. 2000) |
| Psychological morbidity, CIS-R (Lewis et al. 1992) |
| Demographic information (ethnicity, educational qualifications, living arrangements- CSRI (Beecham, 2009) |
| Young person's self-completion questionnaire |
| ADHD rating scale for adults (self-report version) (Barkley and Murphy 1998) |
| Mood lability scale, CNS-LS (Moore et al. 1997) |
| Drug use questions (from 'Mental health of children and young people in Great Britain, 2004') (Green 2005) |
| AUDIT Consumption Questions, AUDIT-C (Bush et al. 1998) |
| Problems with police questions, from ONS 2000 (Singleton et al. 2001) |
| Parent interview: face-to-face |
| ADHD rating scale for adults, Barkely's, informant version (Barkley and Murphy 1998) |
| Background information (marital and tenure status, living arrangements- CSRI) (Beecham, 2009) |
| Needs assessment, CANDID (Xenitidis 2003) |
| Service use (CSRI, Beecham, 2009) |
| Impact of child's/partner's condition on employment (CSRI, Beecham, 2009) |
| General health and wellbeing, SF-12 (Ware et al. 1996) |
| Carer burden, Zarit Carer Burden interview (Bedard et al. 2001, Zarit et al. 1980) |
| Joint interview (young person and parent/partner): face-to-face |
| ADHD diagnostic interview, DIVA (Kooij and Francken 2007) |
| Service use and transition from child to adult services, CSRI (Beecham, 2009) |

The following section describes each of the measures used in this study in more detail.

5.6.2 The Diagnostic Interview for ADHD in adults (DIVA)

The Diagnostic Interview for ADHD in adults (DIVA) is a structured diagnostic instrument developed by Kooij and Francken in 2007 (Kooij and Francken 2007). It investigates the DSM-IV criteria of ADHD in childhood and adulthood, as well as impairment in five areas of functioning in both life periods. In order to facilitate understanding of the criteria in daily life in both childhood and adulthood, every DSM-IV criterion is accompanied by several examples that can be probed. The same is true for the five areas of impairment: education, work, social relationships, social activities/leisure time, partner/family relationships and self-esteem. This study was interested in following up young people who had already received a childhood diagnosis of ADHD and therefore it was deemed unnecessary to confirm this childhood diagnosis at follow-up. Thus, only current symptoms (e.g. in the previous six months) were assessed.

Given that there is currently no measure of ADHD symptoms and impairments that is validated for use across the whole age range used in this study (e.g. 14 to 21) the DIVA was chosen for several reasons. Firstly, despite being a relatively new measure, it was used in preference to existing published diagnostic interviews such as the Conners' Adult ADHD Diagnostic Interview for DSM-IV (CAADID) (Epstein et al. 2001), because it was briefer, permitted greater freedom in responses and is used increasingly throughout Europe. Secondly, compared to the CAADID, which has items that are very similar to the DIVA, the DIVA was also currently publicly available. Thirdly, the items in the DIVA were considered to be more realistic for the diagnostic assessment of ADHD in adults by the European consensus group (Kooij et al. 2010). Lastly, it was judged important to keep the outcome data the same across the whole sample, rather than choose one measure for adolescents and one for adults.

5.6.3 ADHD rating scale for adults

The ADHD rating scale for adults (Barkley and Murphy 1998) is a standardised and widely used rating scale for the assessment, diagnosis and monitoring of treatment of ADHD in adults. It comes in two formats, one for self-report ratings and the other for observer ratings;

both of which were used in this study. Both assess the same 18 symptom items from the diagnostic criteria for ADHD in the DSM-IV.

The two scales ask the informant or person providing a self-report to rate the frequency and severity of specific behaviours that are common in ADHD. The scores are on a 4 point scale ranging from 0 to 3 capturing the severity and frequency of the behaviours representing Not at all or Rarely, Sometimes, Often and Very Often, respectively. It further asks about an estimate of age of onset when these behaviours first were noticed and about the effect of these behaviours on daily living. Participants can complete two versions of this scale, one for current symptoms (over the last 6-months) and the other for recall of childhood symptoms between the ages of 5 to 12 years. As this study was interested in following up young people who had already received a childhood diagnosis of ADHD, it was deemed unnecessary to confirm this childhood diagnosis at follow-up. Therefore, only current symptoms (e.g. in the previous six months) were assessed.

Norms for both current and childhood recall versions are available (Murphy and Barkley, 1996) and validity of the scale has been demonstrated through past findings of significant group differences between ADHD and control adults (Barkley et al. 1996b). An earlier DSM-III version of the scale also correlated significantly with the same scale completed by a parent ($r=.75$) and completed by a spouse or intimate partner of the ADHD adult ($r=.64$) (Murphy and Barkley, 1996).

Parent reports and scores are a commonly used strategy to collect information about behavioural disorders in children that is considered reliable (Faraone et al. 1995). A study by Kooij and colleagues compared different measures and concluded that adults are the best informants for their own symptoms (Kooij et al. 2008). Use of both self-reports and parental reports to assess past ADHD symptoms is a common practice and their agreement has been estimated as moderate (Dias et al. 2008).

5.6.4 The Clinical Interview Schedule-Revised (CIS-R)

The Clinical Interview Schedule-Revised (CIS-R) (Lewis et al. 1992) is a standardised, valid and reliable structured diagnostic instrument used for rating comorbid psychological symptoms. It was developed from an existing instrument, the Clinical Interview Schedule (CIS), which was designed for the use of clinically experienced interviewers such as

psychiatrists. The CIS was revised and developed into a fully structured interview in order to increase standardisation and to make it suitable to be used by trained lay interviewers carrying out assessments in the community, general hospital, occupational and primary care. The CIS-R has proved to be a valid instrument for detection of common mental disorders and has been translated into many other languages and used in several countries (Lewis et al. 1992). It was used by researchers conducting the ONS Psychiatric Morbidity Survey 2007 which aimed to collect data on mental health among adults aged 16 and over living in private households in England. This survey is now the primary source of nationally representative information on the prevalence of both treated and untreated psychiatric disorders and their associations: data which cannot be obtained from other sources.

The CIS-R is designed to assess the prevalence of symptoms of neurotic psychopathology in the previous week. It is made up of fourteen sections, each covering a particular area of neurotic symptoms: fatigue, sleep problems, irritability, worry, depression, depressive ideas, anxiety, obsessions, concentration and forgetfulness, somatic symptoms, compulsions, phobias, worry about physical health and panic. Each section of the CIS-R starts with the establishment of the existence of a particular symptom in the past month. A positive response leads to a more detailed assessment of the symptom in the last week regarding frequency, duration, severity and time since onset. The answers to these questions determine the informant's score on each section. The minimum score on each section is zero where the symptom was either not present in the past week or was present only in mild degree. Symptoms are regarded as severe when the score is 2 or more with a maximum score on each section being four (five for the section on depressive ideas). A total score of less than 12 indicates the presence of no clinically significant neurotic symptoms in the week prior to interview.

Although the CIS-R has not been validated for use in people under the age of 16 this study chose to use this measure in the youngest participants in the sample (e.g. 14-16 year olds) as apart from capturing important aspects of psychopathology, the use of the CIS-R across the whole sample allowed for the same data to be collected and comparisons to be made across the age groups. Unfortunately, to the author's knowledge, there was no measure of psychopathology that has been validated in children, adolescents and adults.

5.6.5 The Camberwell Assessment of Needs for Adults with Developmental and Intellectual Disabilities (CANDID)

CANDID (Xenitidis 2003) is a needs assessment instrument which has been developed for adults with developmental and intellectual disabilities who also have mental health problems. The Camberwell Assessment of Need approach to needs assessment was originally developed for people with severe mental health illness in the form of the Camberwell Assessment of Need (CAN) (Phelan et al. 1995) in relation to the requirements of the National Health Service and Community Care Act (House of Commons, 1990). Since then a number of variants have been developed, based on the same principles, to assess the needs of various subgroups for the assessment of people with mental health problems who are in contact with forensic services (e.g. CANFOR) (Thomas et al. 2003); CANDID, described here in detail (Xenitidis et al. 2000); CANE, for the assessment of older people and particularly those with mental health problems (Orrell and Hancock 2004); and most recently, CAN-M, for the assessment of pregnant women and mothers with severe mental illness (Howard et al. 2007) (all of the above can be found on the Royal College of Psychiatrists website: <http://www.rcpsych.ac.uk/>).

There is currently no “gold-standard” measure for assessing needs in young people with ADHD at transition from childhood to adulthood; however, given that ADHD is a developmental disorder, is often associated with intellectual (learning) disabilities and mental health problems often co-exist (comorbidities), it was judged that the CANDID would be the most appropriate of the available needs assessment instruments. It is a comprehensive instrument that covers a wide range of needs of people with developmental disabilities. Previous needs assessments only indirectly assessed needs of people with learning disabilities and several of them were also lengthy and required special training for their administration. To the author’s knowledge, as with the CIS-R, there was no needs assessment that had been validated for use in the youngest participants involved in this study (e.g. 14-16 year olds). It was felt important to use the same measures across the sample in order to permit comparisons to be made when analysing and interpreting the data.

Two conceptual issues underlie the difficulty in measuring need and are particularly relevant in people with ADHD. First, there is no consensus about the definition of need (Xenitidis 2003). People with developmental disorders such as ADHD often have a complex constellation of difficulties which include not only the needs specific to the core ADHD

symptoms but also, as we have seen, secondary and comorbid difficulties that often emerge and are maintained to a greater or lesser extent because of the core symptoms. ADHD also contains a large spectrum of difficulties; with some people having combined inattentive and hyperactive/impulsive symptoms while others have only inattentive or hyperactive/impulsive symptoms. It is therefore likely that a range of needs are involved in ADHD arising from a variety of factors. There is also a lack of consensus about who should assess need. Some argue that need can only be assessed by professionals (Mooney 1986), whereas others (Bradshaw 1972) claim that individuals' assessment of their own ('felt' and 'experienced') needs is valid. The importance of taking the views of service users has been emphasised, especially as they are known to differ systematically from those of other assessors (Slade 1994). This may be particularly crucial when investigating why people with ADHD use (or do not) services as their own assessment of their needs is likely to be a strong determinant of whether or not they seek help from services. Similarly, the views of mothers of young people are also likely to be important determinants of service use among this group, especially among young people under 18 and those still living at home with their mother who is legally responsible for their wellbeing. Consequently, given the combination of cognitive impairment, age and behavioural disorders exhibited by the participants of this study, and the evidence that young people with ADHD frequently underreport their symptoms (Barkley), it was considered appropriate to collect information on needs from both the young person, but to also collect this information from someone who knows them well, such as their parent or carer.

The CANDID consists of questions on need in 25 domains of the person's life assessing basic needs (accommodation, food); health needs (physical health, major mental health and other mental health, drugs and alcohol, safety to self and others treatment, information about disorder); social needs (social networks, intimate relationships, sexual expression); and everyday functioning (looking after home, self-care, daytime activities, basic education, money budgeting, transport, benefits). It also assesses safety to others and risk of exploitation. The questions are divided into four sections: (a) section I assesses the absence or presence of need and, if need is present, whether it is met or not met; (b) section II rates the help received from informal carers; (c) section IIIa asks about how much help local services are providing and IIIb about how much help the respondent believes that the person needs from local services; and (d) section IV asks about the respondent's satisfaction with the type

(IVa) and amount (IVb) of help received from local services. The CANDID has been rigorously developed and tested by a multidisciplinary team at the Institute of Psychiatry in London (Xenitidis et al. 2003).

The assessment using CANDID involves the interviewer asking the interviewee questions about each of the 25 domains with the interviewer filling in the measure. Questions are asked about each domain, to identify (i) whether a need or problem is present in that domain; and (ii) whether the need is met or unmet. On the basis of the interviewee's responses, a need rating is made: 0= no serious problem (no need), 1=no/moderate problem due to help given (met need), 2=serious problem (unmet need), and 9= not known. In other words, a need is met if there is currently not a problem in the domain, but a problem would exist if it were not for the help provided (i.e. they are getting effective help). A need is unmet if there is currently a problem in the domain (whether or not any help is currently being provided).

Three established needs assessment instruments have been developed in general adult psychiatry in the UK (the MRC-NCA, the CNS and the CAN). All are deemed to have satisfactory psychometric properties. The CAN is recommended over the others due to its advantages by virtue of the various adaptations that have been validated with specific populations, it takes a short time to complete and it is currently the most widely used of the three instruments. Other advantages are its ease of use in research settings and its allowance of the views of different respondents to be recorded and compared in a systematic fashion (as opposed to the integration of responses adopted in the MRC-NCA and the CNS).

A key advantage of the CANDID is that it takes into account not only the service users' problems, but three other considerations: (1) help provided by relatives and services; (2) perceived need for help from services; and (3) adequacy of, and satisfaction with, help provided- for a total of four sections.

5.6.6 A brief series of questions on drug use

This study investigated drug use through a series of questions adapted from the Office of National Statistics survey 'Mental health of children and young people in Great Britain, 2004' (Green 2005). Questions on drug use from this survey were considered briefer and more appropriate than the equivalent questions on drug use used in the Adult Psychiatric Morbidity Survey 2007 (McManus et al. 2009).

Young people were asked to self-rate the frequency and nature of drug use from a range of drugs such as Cannabis, Cocaine and Heroin (see section C in Appendix E). For each individual drug, a question was asked regarding whether the participant had ever used this drug, even if just once. If the young person answered yes to this first opening question two more questions were asked including (i) at what age the young person had first used this drug and (ii) whether or not the young person had used this drug in the last month. It was felt that these questions were best asked in a self-completion format due to the sensitive nature of these questions.

5.6.7 AUDIT Consumption Questions (AUDIT-C)

Alcohol use was assessed using the AUDIT-C (Bush et al. 1998); a brief and validated three questions screen that can help identify hazardous and harmful drinking (please see Section D in Appendix E) (Bradley et al. 2007, Bradley et al. 2009). The AUDIT-C is an abbreviated version of the 10 question Alcohol Use Disorders Identification Test (AUDIT); the only screening instrument of hazardous alcohol use specifically designed for international use that is consistent with ICD-10 definitions of alcohol dependence and harmful alcohol use. Higher scores indicate greater likelihood of hazardous and harmful drinking and may reflect greater severity of alcohol problems and dependence, as well as a greater need for more intensive treatment.

5.6.8 A brief series of questions on problems with police

Problems with police were examined through a series of questions based on those in the background information questionnaire used in the Adult ADHD service at the Maudsley Hospital (adapted for this study). Again, as with the questions about drug and alcohol use, young people were asked these questions in the self-completion questionnaire (see section E in Appendix E). All participants were asked whether or not they had been in trouble with the police in the last 12 months. Those who answered yes were asked a brief series of questions regarding the nature and frequency of these problems (e.g. frequency of custodial sentences, times spent in a prison cell, appearances in court).

5.6.9 The Zarit Carer burden Interview (ZBI)

This study assessed carer burden using the 12-item version (short) of the ZBI (Bedard et al. 2001, Zarit et al. 1980), one of the most widely used tests of caregiving burden. Like the original full 22-item questionnaire, it is a self-reported measure and consists of questions on three dimensions of burden: effect on the social and personal life of caregivers, psychological burden and feelings of guilt. Each question consists of a statement and the respondent is asked to state how they sometimes feel when they are taking care of the person by circling the word that best describes how often they feel that way. Although there are other measures, the 12-item Zarit Burden Interview (ZBI) is the most widely used tool for measuring the level of subjective burden among carers (Higginson et al. 2010). The shorter version has been shown to produce results comparable to those of the full version (correlations between the short and full version have been reported to range from 0.92 to 0.97 (Bedard et al. 2001), and it has recently been endorsed as the best short-form version of the original (Higginson et al. 2010). For these reasons, the briefer version was preferred over the original version.

5.6.10 The Client Service Receipt Inventory (CSRI)

A modified version of the CSRI (Beecham and Knapp 1992) was used to assess service use and transitions from child to adult services. The CSRI is a widely used semi-structured questionnaire of service use which, since it was first used in 1986, has been applied in over 150 health and social care studies. The questions are tailored to suit the data collection requirements of individual research projects, thus permitting a considerable degree of flexibility and adaptability to different research and service contexts.

The CSRI consists of a series of questions about a range of services used in a defined space of time (e.g. the last three months in the present study). The retrospective period (prior to the date of the interview) chosen was a compromise between the accuracy that comes from not asking respondents to cast their minds back too far and the comprehensiveness which can only come by allowing sufficient time to elapse for some uncommon but potentially expensive services to be used. Using the CSRI as part of a face-to-face interview allowed for probing and clarification during the interview which enabled the researcher to record accurate answers. For example, when the family were unsure about what services they had seen (e.g. psychiatrist or psychologist) this could be explored together with the researcher through clarification and further questions.

The adapted CSRI also contained a background section consisting of socio-economic, professional, and demographic questions relating to the young person; a household section which enquired about tenure, number of occupants in the household, and the age of the occupants; and an employment section which asked about the parents and the young person's employment status and the hours worked per week. The second half of the measure contained questions regarding the young person's receipt of services. This included a wide range of services were chosen which were deemed as being relevant to this clinical group, including primary care, community and hospital healthcare and social care services. A third section collected information on education asking whether or not the young person had educational needs and had had any school exclusions or suspensions (and if so, how many times).

In addition to the above sections, a further final section to the CSRI was added, to examine the transition from child to adult services. This section was based on an existing questionnaire assessing transitions from child to adult services designed by a team of researchers at the Social Policy Research Unit, York University (Sloper et al, 2008). Although this measure was not designed for use in young people with developmental disorders, it nevertheless appeared to fit the research agenda of this study. The leader of the research team at York University was contacted about the possibility of modifying the existing measure for use in this study and this was fully granted over email.

Participants were asked if they were still in contact with services and whether this service was a child, adult or non-age specific service. Parents and the young person were also asked if they had moved (or were currently planning a move) from a child to an adult service, and if they had received (or were currently receiving) any support from services in regards to moving to adult services. Moreover, families were also asked about the nature of, and need for, support from services and if they were satisfied with the support they received during the move from child to adult services (see section D in Appendix G). Detailed questions regarding help received or needed were asked of both parents and young people with responses recorded in terms of help not needed yet, got enough help, and needed or need more help. Furthermore, the respondents were asked to give an overall rating of services they had received to indicate if they were very satisfied, satisfied, not satisfied, or not at all satisfied. They were also asked how well the process of moving from child to adult services had been managed.

The benefit of carrying out the CSRI jointly with parents and young people in this study was that they were able to prompt each other, in cases where it was difficult to remember which services had been seen or when these had been used. This is especially so for those participants who were under the age of 18 who were still under the care of their mother. In these cases, the parent, who was still legally responsible for the young person's wellbeing, was more involved in making treatment decisions for their child than the young person themselves and had better recall of service use. However, every opportunity was given to also let young people themselves answer the question.

5.7 Procedure

This section describes how the above measures were piloted prior to data collection and thereafter gives a detailed description of the data collection process and the ethical considerations involved in carrying out this study.

5.7.1 Piloting

Following the design and development of the interview measures the completed interview booklets were piloted at the Adult ADHD Clinic, Maudsley Hospital (South London and Maudsley NHS Trust) in January 2009. This is a clinic with close links to the Institute of Psychiatry comprising a clinical team many of whom linked to the wider NIHR project. A sample of patients (n=8) who were monitored at the clinic for their ADHD symptoms and who were aged 18 to 24 years were contacted regarding participation in the pilot study if they were due to come in to the clinic for a follow-up appointment. All these contacted patients agreed to participate and a time for piloting that was convenient for the participant was arranged (usually immediately following the follow-up appointment at the clinic).

Pilot interviews were conducted over a period of four weeks resulting in a positive overall response to the instruments and interview design. Most of the questionnaires worked well and the actual interviewing stages themselves (both face-to-face interviewing and self-completion questionnaire) were positively received by the participants, many of whom commented positively about the study in terms of potential benefits that the study could bring (i.e., in improving services and treatments for adults with ADHD).

However, while carrying out the pilots it became clear that some of the measures were not capturing enough information to address the research questions adequately. The CSRI, which records use of services, was not adequately capturing information on service use during the transition from child to adult services. Hence, this questionnaire was amended to include a series of questions on transition adapted from a questionnaire specifically addressing the transition from child to adult services designed by a group of researchers at York University. Questions on the transition from child to adult services were consequently added to the existing CSRI booklet (Sloper et al, 2008) (see Appendix G).

The feedback from the respondents during the pilot regarding the clarity, length, content and relevance of the main instrument was largely positive. One exception was the CNL (mood questionnaire) which formed part of the self-completion questionnaire, which was amended after several of the respondents reported that they did not fully understand the instructions (this instrument was not used in this study). Overall, despite the average duration of the young person's interview and completion of the self-completion questionnaire being on average around 1 hour and 20 minutes, all respondents appeared engaged in the interview and commented positively on the research afterwards. The majority of participants reported that they were pleased that this research was being carried out. They felt that services for adults with ADHD were currently lacking and that their needs were currently misunderstood or not fully recognised by health professionals or service providers.

5.7.2 Data collection

Actual data collection was conducted between April 2009 and January 2011 by the researcher and one full-time research assistant (RA). It was essential to recruit one RA as data collection was highly labour-intensive and required the participants to each set aside two hours of their time. Having two, instead of one researcher conducting the interviews enabled the young person and parent interviews to be conducted at the same time minimizing the time the researcher spent at the families' homes whilst ensuring confidentiality during the interview process.

All data collection was coordinated and reviewed by the researcher who ensured, for example, that the data was collected and stored safely and that any research issues could be addressed accordingly.

5.7.3 The interview

The researcher introduced the study, asking participants if they had read the information sheet and had any questions. Depending on the amount of information the parents had obtained regarding the study, the researcher gave either a brief or detailed summary of the reasons for the study and the benefits and disadvantages of participating, including the monetary reward at the end of the approximately two hour home visit, and the potential benefits for informing future service delivery for people with ADHD in childhood and adulthood. The researcher also stressed that all information would be anonymous, they could withdraw participation at any time, and they could choose not to answer certain questions without giving a reason. Following this, written consent was obtained from both the parent and the young person and two separate rooms were chosen for the interviews.

Following the young person interview a self-completion questionnaire was administered to the young person who was told to take his/her time in completing the questionnaire and to join the researcher in the other room with his parent/partner once the questionnaire had been completed. The participant was also told that they could come in to ask any questions or clarification while filling in the questionnaire or to complete the questionnaire at a later time (should they wish to do so, returning the questionnaire in a pre-stamped addressed envelope which once received by the researcher would result in the researcher sending the young person a gift voucher via post; please see 5.7.4). The third and final part of the interview consisted of the joint interview with both the young person and the parent/partner present.

To help elicit the most accurate information regarding types and frequencies of services used, participants were sometimes helped in establishing the type of professional seen. For example, a common confusion was observed regarding whether a psychologist or a psychiatrist had been seen. In such cases, parents were asked if they still had a letter received from the professional that could help answer the question. They were also asked if they could remember what had occurred during their visit to the professional (e.g. in this way helping the researcher to establish, for example, if the professional had prescribed medication or been more medically orientated, i.e. a psychiatrist). When participants were unsure about the number of times they had seen or visited a professional/service the decision was made to underestimate the visits rather than overestimate.

5.7.4 Childhood data

Data on child ADHD symptoms, family socioeconomic status (SES) and childhood conduct disorder were taken from the IMAGE research database. The measure used to assess ADHD symptoms and conduct disorder were the Conner's Parent Rating Scales and the Strengths and Difficulties Questionnaire (SDQ). SES was based on parental occupational status and category of the greater of the two parents. A 5-point scale was used: 0 = not in search for a job (housewife/husband, disabled/on disability allowance, other); 1= unemployed but in search for a job; 2= employed labourer; 3 = employed in service or sales; 4 = employed clerk and 5= employed professional.

5.7.5 Reimbursement

Following the interviews, a £20 gift voucher was given to the young person as a thank you for their time (this was initially £10 but was increased to £20 following poor response rates to the invitation letters).

5.7.6 Ethical considerations

This study, involving adolescents and young adults with ADHD and their parents, received ethical approval from the Ethics committee of the South London and Maudsley NHS Trust and Institute of Psychiatry (Study No: 08/H0807/68) (The ethical approval letter is shown in Appendix A). There were some considerations to the good ethical conduct of this study, for both the face-to-face interviews and the self-completion questionnaires. These considerations were largely related to informed consent, confidentiality and minimizing any potential discomfort that may have arisen from taking part in the study.

In order to enable informed consent, families were given information about the benefits and harms of participating in the research and ensured that no undue influence or coercion to participation exists (Singer, 2008). Both young people and parents were sent Information Sheets (Appendix B) with information about the aims and objectives of the study and what participation would involve. Participants were specifically told that participation or refusal in the study was completely voluntary and that all personal information would be regarded as strictly confidential and kept secure until the research was completed. The information sheets and consent forms also informed families that they were free to stop participation and to have any research data withdrawn without giving any reason. However, once analysis of the

anonymised data was under way it would not be possible to have data withdrawn. Informed consent was gained first verbally via telephone and then through a written consent form on the day of the interview (Appendix C).

No foreseeable risks were anticipated from the study other than the inconvenience of taking part and some possible discomfort arising from answering some of the questions which may have been regarded as distressing. The information sheets informed participants of these potential disadvantages and reassured them that in the unlikely event that any distress was caused to the participant, the interview could be terminated at any time. To minimize the risk of any possible harm or discomfort every effort was made to make the interview process as comfortable and convenient for the participants as possible. The researcher was, for example, keen that both the young person and parent found the time and place of the interview to be convenient and in the rare instances where participants became fatigued, participants were encouraged to have a break and to continue only when they felt comfortable.

In addition, a structured but flexible interview was selected as the most appropriate method to achieve the stated aims of this study due to some of the sensitive questions contained in the study. The use of the name of the young person in the interview process helped to focus the interview on the individual experience and establish a rapport between the interviewer and participant. In the design of the interviews, every effort was made to ensure that the length and language of the interview was appropriate and easy to understand. Care was taken to ensure that measures would not include long sentences and difficult terms that may have been difficult to understand. Potentially sensitive questions regarding drug and alcohol use and problems with police were placed in the self-completion questionnaire.

5.8 Data management and analysis plan

This section describes data management for this study before outlining the plan of descriptive, univariate, and multivariate analyses used in this study.

5.8.1 Data management

All data collected during the participant interviews were stored safely in a locked cupboard near the researcher's office desk at King's College London, with only the researcher and the immediate research team having access to the data. An SPSS (version 17) database was

created by the researcher and her supervisor containing predetermined codes and where a structure for the data was agreed. This database was thereafter sent to a data entry company who entered all data onto the database following the researcher's specified codes and structure. Data were delivered to the researcher in the SPSS database and checked for accuracy by a process of (i) checking that maximum and minimum scores for all variables were within the expected range, (ii) checking all scores for a randomly selected 10% of cases. Unfortunately, a significant number of errors in the data entry were found. Therefore the researcher and a placement student re-checked all data entries against hardcopies of the data (including over 1000 variables per family) and corrected any identified errors.

To deal with missing or inconsistent data in the self-completion questionnaire, the researcher attempted to clarify responses during the home visits. For example, if the participant had not selected any response category, the researcher asked if this was because they felt that the question did not apply to them or because they were unsure how to respond (or had missed this question). Participants frequently skipped over a question in Section A of the self-completion questionnaire (question 2) because they felt that this question did not apply to them (e.g. how impaired they were in driving a vehicle was not applicable if the participants were too young to drive). In such cases, the researcher was able to clarify this with the young person and record this as 'never' rather than 'missing'.

In cases where data was missing or incomplete and the researcher was not able to spot this because the participants had chosen to complete the questionnaires at a later date and had therefore sent back the completed questionnaire in the post, the researcher had to make certain rules as to how to deal with missing or inconsistent data. For example, if participants selected more than one numerical category, such as in the alcohol measure (Appendix E), the category with the higher number was recorded. Likewise, if participants circled more than one response in questions regarding the severity or frequency of symptoms or any outcomes of interest the response with the higher number, indicating more severe symptoms was recorded. These latter rules applied to all recording of data involving numbers where participants were unsure or were unable to remember the exact number of times that an event had occurred.

Once the data were cleaned and checked for missing information, the dataset was analysed on a secure password protected computer using SPSS Version 17.0 (SPSS for Windows, 2008).

5.8.2 Plan of analyses

All families with both young person and parent data were included in the analyses (n=82). Out of the 92 families who participated in the study, six families had to be excluded from the analyses as they gave only young person data (n=1) or parent data (n=5). Unfortunately, four additional families also had to be removed from the final analyses as it was later discovered that they had failed to meet all inclusion criteria for participation in the childhood IMAGE study, resulting in a total of 82 families included in the final analyses. A post-hoc power calculation revealed that this study can detect differences in service use between 14 to 17 and 18 to 21 year olds with 89% power (<http://clincalc.com/Stats/Power.aspx>).

This study used both bivariate and multivariate statistical techniques. As a first step descriptive analyses are presented (percentage distributions for categorical data and mean and standard deviations for continuous data) describing the socio-demographic and health characteristics of the sample (young person and parent). As well as the distribution of ADHD symptoms, the needs of the sample, health service use and healthcare transitions are also described. Second, t-tests for continuous variables and Chi-square tests for categorical variables were used to examine associations between those who still met the diagnostic threshold for ADHD and those who did not in relation to this study's variables of interest: neurotic symptoms, drug and alcohol use, problems with police, impairment, needs and health service use. Where variables were not normally distributed (e.g. CIS-R score representing psychological comorbidities and need as measured by the CANDID) non-parametric analyses were initially conducted (e.g. using the Mann Whitney U test). However, given that the non-parametric and parametric tests showed similar results only the parametric tests are reported here given their wider familiarity and greater ease of interpretation (e.g. t-tests versus Mann Whitney U, Pearson's versus Spearman's correlation coefficients). Data on service use were also described by age, due to the theoretical importance of this variable for this study. A p value of <.05 was considered statistically significant.

Third, this study used linear regression to examine the factors associated with this sample's overall level of impairment. The independent variables chosen in the linear regression model included inattentive symptoms (which, as discussed in Chapter 2, have been shown to persist into adulthood more frequently than hyperactive/impulsive symptoms which tend to diminish); individual needs in safety of self, inappropriate behaviour and communication

domains as measured with the CANDID (as these individual needs were considered to overlap less with the impairment variable than the ‘total needs variable’ and the impairing effects of individual needs were not known). Finally, carer burden and problems with police were added to the inattentive symptoms and need variables as it was unclear to what extent these would be associated with impairments.

Finally, multivariate logistic regression analysis was used to examine the relationship between theoretically important predisposing, enabling and need factors and health service use: the main outcome of interest “health service use” was dichotomized into those who were still in touch with services and those who were not. Correlates of health service use were chosen from Andersen’s behavioural model of health service use capturing predisposing (age), enabling (mother’s education, place of family residence, information about ADHD) and need factors (Inattentive symptoms, hyperactive/impulsive symptoms, neurotic symptoms, impairments, needs, childhood conduct disorder, carer burden). The operationalisation of these variables, as well as the final model presented, are discussed in Chapter 8. Significance tests were quoted as two-tailed probabilities with significance levels of $p\text{-value} < .05$ being used. Results are given in the form of odds ratios (OR) for the variables alongside 95% confidence intervals CI (C intervals) and the level of significance, in this way presenting the effects of a given independent variable on the odds of the outcome being examined taking into account the other factors in the model. The goodness of fit of the model was also investigated using the Hosmer-Lemeshow test.

The next chapter will present findings regarding the socio-demographic and health characteristics of the sample, including the sample’s ADHD symptoms, comorbidities and impairments.

CHAPTER 6

Sample characteristics and levels of impairment

6.1 Outline of results chapters

This first (of three) results chapter gives an outline of the socio-demographic characteristics of the sample and examines whether the participants, now aged 14 to 21 (who were previously diagnosed with combined-type ADHD in childhood), are still symptomatic. It further explores the additional ‘burden’ associated with ADHD diagnosis among this group in terms of psychological comorbidities (such as anxiety and depression), drug and alcohol use, problems with police and impairments. Among other things, this chapter shows the persistence of ADHD among this group at ages 14 to 21: over 70% continued to meet diagnostic criteria for ADHD, of whom around one third met criteria for combined-type ADHD (both inattentive and hyperactive/impulsive symptoms) and another third met threshold for inattentive-type ADHD. There were significant differences between participants who continued to meet diagnostic threshold for ADHD and those who did not in levels of psychological comorbidities and impairments, but not in current drug and alcohol use or problems with police.

The second results chapter, Chapter 7, then addresses the first research question, focusing on the needs of the participants, which will include but not be limited to, those arising from ADHD diagnosis. Specifically, it identifies needs of the study participants in a range of life domains covered in the CANDID and seeks to demonstrate to what extent these needs were being met by services (“services” used here to denote all services in line with the use of the term in the CANDID as discussed on p. 2) and the young person’s friends and family members. This chapter shows that the study participants had a range of needs which went beyond those purely related to their ADHD and that these needs were largely unmet by services, with families providing most of the help received towards meeting these needs.

The third and final results chapter, Chapter 8, provides a description of health service use and transition from child to adult health services, addressing the second and third research

questions. It describes the current use of child, adult, and non-age specific ADHD services among the sample and examines predisposing, enabling and need factors associated with health service use using bivariate and multivariate statistical techniques. It also examines healthcare transition in terms of the young people's transfer from child to adult health services and the support that these young people and their families received from health services during the transition process.

As noted in Chapter 5, all three results chapters have been structured in such a way as to investigate differences between participants who still met the diagnostic threshold for ADHD and those who did not. In addition, as participants age ranged from 14 to 21 years and 14 to 15 year olds, 16 to 17 year olds and 18 to 21 year olds are likely to be at different stages of their transition pathway, sensitivity analyses are carried out for key analyses- initially omitting 14 and 15 year olds and then omitting 14 to 17 year olds to see if the findings hold.

6.2 Statistical analyses

This first results chapter provides a background to the sample, presenting findings from the participant interviews and self-completion questionnaires regarding the socio-demographic and health characteristics of the sample. These were investigated using both descriptive and inferential statistics, mainly percentage distributions and means and standard deviations for categorical and continuous data respectively and chi-square tests and t-tests to examine differences between those who still met the diagnostic criteria for ADHD and those who did not. Pearson's correlations and linear regression were also used to explore which factors were associated with impairments in this sample.

6.3 Socio-demographic characteristics

Key socio-demographic characteristics of the sample are outlined in this section. A more comprehensive list of socio-demographic characteristics can be found in Appendix H.

6.3.1 Sample participants and response rate

The sample consisted of 164 participants of whom 82 were young people with a previous diagnosis of combined type ADHD and 82 were parents (mostly mothers) of these young people. An additional ten families were also interviewed for the study; however they were excluded from the final analyses. This was because six of the ten families contained only

parent (n=5) or young person data (n=1) and only participants with both parent and young person data were chosen. In addition, four participants were excluded as it was subsequently found that they did not meet the original study criteria for ADHD in childhood. Therefore, out of the total 154 families, an overall response rate of 53% was achieved (63% if counting only those who were contactable) resulting in the collection of parent and young person data from 82 families.

All of the measures used in this study were completed by most families however there were some missing data. Apart from the needs assessment measure (CANDID) which was completed by all 82 families all other measures contained some missing data. In the case of the DIVA, two families failed to complete the interview as the interviews had to be terminated abruptly, resulting in 80 families who provided data on ADHD symptoms. One of these families also failed to complete the CIS-R, resulting in complete information on neurotic symptoms for 81 families. In addition to these missing data, six young people failed to complete all of the questions on the self-completion questionnaire resulting in 76 participants completing all questions on drug and alcohol use and 77 participants completing all questions regarding problems with police. There were also some missing data for seven families in the Joint Interview where missing data mostly related to questions on young person's transition needs and where the young person failed to give all answers (e.g. where the young person was unsure). Lastly, three parents failed to complete the whole parent interview, resulting in incomplete data for three parents in the carer burden measure and in the CSR-I measure about their background (e.g. educational achievement and work).

6.3.2 Age and gender

The mean age of the young study participants was 17.5 years (range 14 to 21 years, sd. 2.3) of whom 36 were in the age range 14 to 17 years and 46 were aged 18 to 21. Of those in the younger age range, 24 participants were aged 14 to 15 and 12 were 16 to 17 years old. The sample consisted of 73 (89%) males and 9 females (11%); that is, a male to female ratio of 8:1. The significantly larger proportion of males in this study is broadly in keeping with previous studies which found that ADHD is more common in males than in females, with ratios ranging from 2:1 to 9:1 depending on the subset of ADHD and the setting (American Psychiatric Association 2000, Biederman et al. 2002, Barkley and Murphy 2006) .

6.3.3 Education/ employment

Most (n=53, 66%) young participants were still attending full or part-time education and a third (n=30, 37%) were in some form of employment. This latter group included those in full-time, part-time, casual and voluntary work (either in addition to studying or solely working). 13 participants (16%) who were no longer in education were unemployed.

There was a high level of educational exclusions in this sample. Nearly half of the sample had received at least one informal exclusion from school/university (n=41) and of these 30% (n=12) had been permanently excluded. This is consistent with previous studies which have shown that children with ADHD are more likely to be suspended and expelled than their peers (August et al. 1983, Barkley et al. 2006, Lambert 1988). In addition, twelve participants (15%) in this study reported that they had a statement of special needs. Previous studies have found that children with ADHD are more likely to attend special schools (Lambert 1988), or repeat a grade compared with their healthy peers (Barkley et al. 2006).

6.3.4 Living arrangements

At the time of the interview, just over half of the participants (n=46, 56%) were living in Greater London and the remainder were living outside this area. The majority (n= 72, 87%) of young people were still living with one or both parents and with at least one sibling (n=66, 80%). Only 2 participants (2%) were married or living with a partner. The remaining participants (n=8, 10%) were either living alone or with relative, friend or non-relative (see Appendix H for details).

6.3.5 Parent characteristics

Nearly all (n=81, 99%) of the parents who participated in this study were mothers. 59 parents were currently married (72%), 13 were separated or divorced (16%) and the remainder were either never married (n=4) or widowed (n=1) or had cohabited (n=2). Forty-two per cent of those who were currently married reported having been in a previous marriage (n=28). Thirty-two per cent of the parents also reported that they were a carer for someone else apart from their child with ADHD (n=25).

The majority (n=49, 63%) of parents reported having achieved either secondary level education or GCSE's while almost a third of parents (n=29, 37%) had reached a level of higher education. Most parents were home owners (n= 63, 80%).

In summary, this study achieved a good response rate of 53% resulting in 82 interviews with young people (with largely complete data for the parent and the young person) now aged 14 to 21 (mean age 17.5 years). The sample composition and characteristics are broadly similar to previous studies that have followed up children with ADHD (Mannuzza et al. 1993, Rasmussen and Gillberg 2000, Weiss and Hechtman 1993).

6.4 Health characteristics

This section focuses on the health characteristics of the sample and begins with a description of whether this sample (all previously diagnosed with combined-type ADHD in childhood) is still symptomatic of ADHD at ages 14 to 21. It thereafter describes the additional 'burden/comorbidities' associated with ADHD (including psychological problems, drug and alcohol use, and problems with police) and examines day-to-day impairments (and associated factors).

6.4.1 ADHD diagnoses according to DIVA

As noted in Chapter 5, symptoms of inattention and hyperactivity/impulsivity in the last six months were assessed using the DIVA, a diagnostic face-to-face instrument of ADHD. Using the DIVA, two subtypes of ADHD can be identified: the predominantly inattentive type and the hyperactive/impulsive type (please see Chapter 5 for details).

Table 6.1 shows the sample distribution of ADHD diagnoses according to DSM-IV diagnostic criteria and differences in diagnosis by age group (14 to 17 and 18 to 21). It shows that in the six months prior to interview the majority of all participants (n=58, 73%) had ADHD symptoms that were frequent and persistent enough to meet the DSM-IV diagnostic threshold for ADHD. It also shows that there was no significant difference in the proportion of participants who fell above and below the diagnostic criteria between the two age groups. However, as expected, a higher proportion of the younger age group met criteria for the Combined ADHD diagnosis than the older age group (41% versus 24%) whereas a higher

proportion of the older age group met criteria for the Predominantly inattentive subtype than the younger age group (43% versus 23%).

Table 6.1 Distribution of ADHD diagnoses by age according to the DSM-IV criteria (column %)

| DIVA (Potential range 0-9) n= 80 | DSM-IV (6 and over) Total sample n (%) | DSM-IV (6 and over) 14 to 17 year olds n (%) | DSM-IV (6 and over) 18 to 21 year olds n (%) |
|---|---|---|---|
| Below diagnostic threshold | 22 (27) | 10 (29) | 12 (26) |
| Above diagnostic threshold, of which: | 58 (73) | 24 (71) | 34 (74) |
| <i>Combined ADHD</i> | 25 (31) | 14 (41) | 11 (24) |
| <i>Predominantly Inattentive subtype</i> | 28 (35) | 8 (23) | 20 (43) |
| <i>Hyperactive/Impulsive subtype</i> | 5 (6) | 2 (6) | 3 (7) |
| Total % | 100 | 100 | 100 |
| (Number) | 80 | 34 | 46 |

According to the DSM-IV diagnostic criteria, the largest proportion of the sample met the diagnostic threshold for predominantly inattentive type ADHD (that is, they had significant inattentive symptoms, but not significant hyperactive/impulsive symptoms). Almost a third of the sample also met the diagnostic threshold for combined ADHD (that is, both significant inattention and hyperactivity/ impulsivity); however, few reached the diagnostic threshold for the hyperactive subtype (significant hyperactive/impulsive symptoms, but not significant inattentive symptoms).

A finer breakdown of the ages of participants according to ADHD diagnosis is seen in Table 6.2 which again shows no significant difference between the age groups in whether or not they met diagnostic criteria. However, there was still a high proportion of 16 to 17 year olds who met criteria for the combined ADHD diagnosis compared with the 18 to 21 year old participants.

Table 6.2 Distribution of ADHD diagnoses by age according to the DSM-IV criteria (column %)

| DIVA (Potential range 0-9) n= 80 | DSM-IV (6 and over) 14 to 15 year olds n (%) | DSM-IV (6 and over) 16 to 17 year olds n (%) | DSM-IV (6 and over) 18 to 21 year olds n (%) |
|---|---|---|---|
| Below diagnostic threshold | 8 (36) | 2 (17) | 12 (26) |
| Above diagnostic threshold, of which: | 14 (64) | 10 (83) | 34 (74) |
| <i>Combined type</i> | 8 (36) | 7 (58) | 11 (24) |
| <i>Predominantly Inattentive type</i> | 4 (19) | 3 (25) | 20 (43) |
| <i>Hyperactive/Impulsive type</i> | 2 (9) | 0 (0) | 3 (7) |
| Total % | 100 | 100 | 100 |
| (Number) | 22 | 12 | 46 |

Thus to summarise, so far, a vast majority (73%) of this sample continued to experience ADHD symptoms that were frequent and severe enough to meet the DSM-IV diagnostic threshold for ADHD. Of these, nearly half continued to experience both significant inattentive and hyperactive/impulsive symptoms while another half continued to experience severe and frequent inattentive symptoms but not hyperactive/impulsive symptoms. Only a small proportion (around a sixth) continued to experience severe and frequent hyperactive/impulsive symptoms.

This is broadly in keeping with previous studies that have followed-up boys with a childhood diagnosis of ADHD. For example, Biederman and colleagues (2006), in a 10-year prospective follow-up study of males that included 140 with and 120 without ADHD (mean age, 21 years) found that a total of 58% of the original ADHD patients and 6% of the controls met criteria for full or sub-threshold ADHD (endorsing four or five symptoms) at follow-up by self-report (Biederman et al. 2006). Moreover, a meta-analysis of follow-up studies published by Faraone and colleagues (2006) also reported similar prevalence rates at follow-up. The meta-analysis investigated the persistence of ADHD based on results from 10 prospective cohort samples and found persistence rates ranging from 40% to 60% (depending on whether or not the researchers included cases consistent with the DSM-IV's partial remission criteria, in which case the persistence was around 60%). Children in these 10 studies were predominantly male and were originally diagnosed between the ages of 4 and 12

years, with the final follow-up taking place when the children were 14 to 30 years of age (Faraone et al. 2006).

6.4.2 Comorbidities

This section focuses on the additional comorbidities of the sample associated with ADHD, including psychological problems, drug and alcohol use and problems with police.

6.4.3 Psychological morbidity according to CIS-R

As described in Chapter 5, psychological morbidity was assessed using the CIS-R where a score of 0-11 (out of 49) indicated the presence of no clinically significant neurotic symptoms, a score of 12-17 indicated a significant level of neurotic symptoms (but unlikely to warrant treatment), and a score of 18 or above indicated symptoms of a level of severity significant enough to warrant treatment (McManus et al. 2009).

Table 6.3 shows the distribution of significant and clinically non-significant CIS-R scores for the 81 participants who completed the CIS-R. 27% of participants in this sample had experienced symptoms indicative of a psychological disorder. Of those who experienced significant symptoms, close to one third (n=7) had symptoms severe enough to warrant treatment.

Table 6.3 Distribution of young person's CIS-R scores indicating neurotic symptoms in the last month (column %)

| CIS-R scores (potential range 0-49) | Total sample n (%) |
|--|-------------------------------|
| No significant neurotic symptoms (0-11) | 59 (73) |
| Significant neurotic symptoms (12+), of which: | 22 (27) |
| <i>Unlikely to warrant treatment 12-17</i> | <i>15 (18)</i> |
| <i>Likely to warrant treatment 18+</i> | <i>7 (9)</i> |
| Total % | 100 |
| (Number) | 81 |

Table 6.4 shows that ADHD in this sample was significantly associated with psychological morbidity (as the CIS-R is not normally distributed the Mann-Whitney U test was initially conducted to examine differences in the score by ADHD diagnosis – as this test also showed

a significant association only the t-test is reported here). This table shows that the mean CIS-R score among those who met diagnostic threshold for ADHD was significantly higher in comparison to those who no longer met the criteria (a mean of 9.0 versus 4.6 respectively, $t=2.81$, $p=.006$).

Table 6.4 Mean CIS-R scores by ADHD diagnosis

| | Total (n=80) | Above threshold (n=58) | Below threshold (n=22) |
|------------------------|-------------------------|-----------------------------------|-----------------------------------|
| Mean CIS-R score (sd.) | 7.9 (6.5) | 9.0 (6.7) | 4.6 (4.8) |

t-test 2.81; p=.006.

Depression scores were significantly higher among those who met threshold for ADHD compared to those who did not meet the diagnostic criteria (a mean of 0.64 versus 0.27 respectively, $t=1.43$, $df.78$, $p=.013$), as were anxiety scores ($t=1.25$, $df.78$, $p=.012$) indicating that not only were items like concentration difficulties, irritability and sleep problems (e.g. items often associated with ADHD) higher among this group but so were depressive and anxiety symptoms. Another possible explanation for these findings is that specific participants under-reported symptoms across domains leading to a false positive finding. In addition, it is worth bearing in mind that this sample was originally recruited from CAMHS clinics in childhood (e.g. rather than paediatrics) which may result in a higher likelihood of them presenting with more mental health problems at follow-up.

Previous studies have found higher depression scores among young people with ADHD (Biederman et al. 1993, Kessler et al. 2006, Klein and Mannuzza 2008) whereas studies investigating the prevalence of mood and anxiety disorders at follow-up in children with ADHD have yielded mixed results. Most studies have found that girls and boys with ADHD have an elevated lifetime and 12-month prevalence of mood and anxiety disorders (Barkley et al. 2006, Biederman et al. 2006, Polanczyk et al. 2007) whereas few have not reported this finding for male ADHD patients (Lambert 1988). Even when this relationship has been reported for male patients with ADHD, upon controlling for baseline age, socioeconomic status, and psychopathology, this result was no longer significant (Biederman et al. 2006). In contrast, when controlling for these variables in female ADHD patients, this relationship remained significant (Biederman et al. 2006).

Tables 6.5 and 6.6 present the mean CI-S scores by age. Although the mean CIS-R score was highest among the 16 to 17 year old group (as shown in Table 6.6) the differences between the scores were not significant.

Table 6.5 Mean CIS-R scores by two age groups

| | Total (n= 81) | 14 to 17 year olds (n= 35) | 18 to 21 year olds (n= 46) |
|------------------------|--------------------------|---------------------------------------|---------------------------------------|
| Mean CIS-R score (sd.) | 7.9 (6.5) | 7.5 (6.4) | 8.1 (6.6) |

t-test -.36; *p*= .719.

Table 6.6 Mean CIS-R scores by three age groups

| | 14 to 15 year olds (n=23) | 16 to 17 year olds (n=12) | 18 to 21 year olds (n=46) |
|------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Mean CIS-R score (sd.) | 6.7 (6.1) | 9.3 (6.9) | 8.1 (6.6) |

ANOVA $F(2, 78) = .71$; *p*= .495.

6.4.4 Drug and alcohol use

As reported in Chapter 5, drug and alcohol use was assessed through a series of questions in the young person's self-completion questionnaire. A combined measure was created to capture any drug use or alcohol problem (defined as a positive response to use of illicit drug in last month and/or hazardous alcohol drinking as measured with AUDIT-C). As seen in table 6.7, 49 participants (66%) of the 74 participants who provided data on their drug and alcohol use and ADHD symptoms, reported either recent drug use or had scores indicative of hazardous drinking (or both), but this problem did not differ significantly between those who met and those who did not meet ADHD criteria.

Table 6.7 Distribution of any drug use or alcohol problem by ADHD diagnosis (column %)

| Any drug use or alcohol problem | Total n (%) | Above threshold n (%) | Below threshold n (%) |
|--|------------------------|----------------------------------|----------------------------------|
| Has a drug or alcohol problem | 49 (66) | 34 (63) | 15 (75) |
| Has no drug or alcohol problem | 25 (34) | 20 (37) | 5 (25) |
| Total % | 100 | 100 | 100 |
| (Number) | 74 | 54 | 20 |

$\chi^2 = .95$; *p*= .331.

The self-report also showed that 47% (n=36) of the sample had used Cannabis at some point in their lives and 22% (n=17) had used it in the last month. 21% (n=16) reported that they had used another drug apart from Cannabis in the past and nine (12%) reported having used another drug apart from Cannabis in the last month. There was no significant difference in drug use by ADHD diagnosis ($t = -.63$, $df = 72$, $p = .535$).

Drug use did, however, as expected, differ significantly by age, as shown in Table 6.8. 90% of those aged 18 to 21 years had recently used drugs or engaged in hazardous alcohol drinking compared with 35% of those aged 14 to 17 years.

Table 6.8 Distribution of any drug use or alcohol problem by two age groups (column %)

| Any drug use or alcohol problem | Total n (%) | 14 to 17 year olds n (%) | 18 to 21 year olds n (%) |
|---------------------------------|----------------|-----------------------------|-----------------------------|
| Has a drug or alcohol problem | 50 (66) | 12 (35) | 38 (90) |
| Has no drug or alcohol problem | 26 (34) | 22 (65) | 4 (10) |
| Total % | 100 | 100 | 100 |
| (Number) | 76 | 34 | 42 |

$\chi^2 = 25.42$; $p < .001$.

When 14 to 15 year olds were omitted from the analysis a significant difference between 16 to 17 and 18 to 21 year olds remained ($\chi^2 = 13.25$; $p < .001$), indicating that there was no significant difference between 14 to 15 year olds and 16 to 17 year olds in recent drug use or hazardous alcohol use.

Older participants (18 to 21 year olds) were more likely, for example, to have used Cannabis in the last month (52% versus 17%; $\chi^2 = 4.30$; $p = .038$) and to have used another drug apart from Cannabis in the past (37% versus 3%, $\chi^2 = 12.57$; $p = .002$). The most commonly used drugs apart from Cannabis among 18 to 21 year olds were Cocaine (23%), Ecstasy (19%), Amphetamines (17%), LSD (6%), Heroin (3%) and Tranquilisers (3%).

Hazardous alcohol use was based on the scores from the AUDIT-C where higher scores indicated greater likelihood of hazardous and harmful drinking. Overall, almost two thirds of the sample had scores that were high enough to indicate hazardous and harmful drinking (65%). There were no significant differences in the percentage reporting hazardous alcohol

use between those who fell above or below the diagnostic criteria for ADHD (61% versus 75%, $\chi^2 = 1.24$, $p = .266$) as seen in Table 6.9.

Table 6.9 Distribution of hazardous drinking by ADHD diagnosis (column %)

| Alcohol use | Total sample n (%) | Above threshold n (%) | Below threshold n (%) |
|--------------------------|-----------------------|--------------------------|--------------------------|
| Hazardous alcohol use | 48 (65) | 33 (61) | 15 (75) |
| No hazardous alcohol use | 26 (35) | 21 (39) | 5 (25) |
| Total % | 100 | 100 | 100 |
| (Number) | 74 | 54 | 20 |

$\chi^2 = 1.24$; $p = .266$.

Again, the older age group were significantly more likely to have scores indicative of hazardous alcohol use than the young age group (88% versus 33% and 40%), $\chi^2 = 22.87$; $p < .001$). This finding still held after omitting 14 to 15 year olds from the analysis ($\chi^2 = 11.20$; $p = .001$).

Table 6.10 Distribution of hazardous drinking by three age groups (column %)

| Alcohol use | Total sample n (%) | 14 to 15 year olds n (%) | 16 to 17 year olds n (%) | 18 to 21 year olds n (%) |
|--------------------------|-----------------------|-----------------------------|-----------------------------|-----------------------------|
| Hazardous alcohol use | 49 (65) | 8 (33) | 4 (40) | 37 (88) |
| No hazardous alcohol use | 27 (35) | 16 (67) | 6 (60) | 5 (12) |
| Total % | 100 | 100 | 100 | 100 |
| (Number) | 76 | 24 | 10 | 42 |

$\chi^2 = 22.87$; $p < .001$.

These high rates in hazardous alcohol use are consistent with previous studies that have followed up boys who were diagnosed as hyperactive in childhood (Mannuzza et al. 1993). As in the study by Mannuzza and colleagues (1993), this study suggests that childhood ADHD predicts adult drug abuse disorders and that, in adulthood, these appear to be, at least in part, independent of sustained ADHD.

6.4.5 Trouble with the police

As described in Chapter 5, trouble with police was assessed through a brief series of questions regarding problems with police as part of the young person's self-completion questionnaire (see Appendix E for details). Overall, over a quarter of the sample (n=20) reported having been in trouble with the police in the last 12 months with main reasons given for this trouble being: drunk and disorderly behaviour (n=3), antisocial behaviour (n=1), speeding/bad driving (n=3), criminal damage and assault (n=2), taking drugs (n=1), graffiti (n=1), possession of a knife (n=1), car vandalism (n=1) and arson on bus (n=1). Table 6.11 shows that there was no significant difference between the percentage of participants who had been in trouble with police in the last year by ADHD diagnosis (25% versus 25%, $\chi^2 = .00$; $p = .988$).

Table 6. 11 Distribution of trouble with the police by ADHD diagnosis (column %)

| | Total sample n (%) | Above threshold n (%) | Below threshold n (%) |
|---|-----------------------|-----------------------------|-----------------------------|
| Been in trouble with police in the last 12 months | 19 (25) | 14 (25) | 5 (25) |
| Not in trouble with police in the last 12 months | 56 (75) | 41 (75) | 15 (75) |
| Total % | 100 | 100 | 100 |
| (number) | 75 | 55 | 20 |

$\chi^2 = .00$; $p = .988$.

Again, there was a significant difference by age where the 18 to 21 year olds were more likely to have been in trouble with police in the last 12 months (40% versus 8% and 9%, $\chi^2 = 10.79$; $p = .005$) as shown in Table 6.12. However, when 14 to 15 year olds were omitted from the analysis the difference was no longer significant ($\chi^2 = 3.83$; $p = .147$).

Table 6. 12 Distribution of trouble with the police by three age groups (column %)

| | Total sample n (%) | 14 to 15 year olds n (%) | 16 to 17 year olds n (%) | 18 to 21 year olds n (%) |
|---|-----------------------------------|---|---|---|
| Been in trouble with police in the last 12 months | 20 (26) | 2 (8) | 1 (9) | 17 (40) |
| Not in trouble with police in the last 12 months | 57 (74) | 22 (92) | 10 (91) | 25 (60) |
| Total (%) | 100 | 100 | 100 | 100 |
| (number) | 77 | 24 | 11 | 42 |

$\chi^2 = 10.79$; $p = .005$.

To summarise, there was a significant association between ADHD and neurotic symptoms but no significant association between meeting ADHD diagnostic criteria and alcohol or drug use or trouble with police. Nevertheless, almost two thirds of the sample reported current alcohol use that was indicative of hazardous levels of drinking; almost half had also used Cannabis at some point in their lives with around a fifth reporting using it in the last month. Over a quarter of the sample had been in trouble with police in the last year, and amongst the older age group this figure rose to 40%.

The next section will examine the day to day impairments of the sample and explore which factors contributed significantly to overall level of impairment.

6.5 ADHD related Impairments (according to Informant Barkley's rating-scale)

As discussed in Chapter 5, impairments in daily living were assessed using the Barkley's self-rating scale (Informant version) (Barkley and Murphy 1998). Parents were asked to rate the frequency of their child's impairments in ten life domains such as home life, school, work, and relationships.

6.5.1 Prevalence of significant impairments in daily activities

Nearly all parents (90%) reported that their child was impaired in at least one life activity. Table 6.13 shows the prevalence of impairments as rated by parents (e.g. with significant impairments indicating impaired functioning in these life activities often or very often as opposed to rarely or sometimes). It shows that the five life activities most affected according

to parents were (in order): management of daily responsibilities (68%); home life (67%); educational activities (62%); management of money (61%); and work or occupation (49%).

Table 6. 13 Prevalence of individual impairments by ADHD diagnosis according to the Barkley's informant scale

| Impaired life activity | Total sample n (%) | Above threshold n (%) | Below threshold n (%) | χ^2 Sign. |
|---|-----------------------|--------------------------|--------------------------|-------------------|
| Management of daily responsibilities | 54 (68) | 40 (73) | 13 (59) | p= .27 |
| Home life with immediate family | 53 (67) | 39 (71) | 12 (54) | p= .04 |
| Educational activities | 44 (62) | 32 (65) | 10 (45) | p= .28 |
| Management of money | 48 (61) | 36 (65) | 10 (45) | p= .43 |
| Work or occupation | 36 (49) | 26 (52) | 8 (38) | p= .63 |
| Social interactions with others | 30 (39) | 22 (41) | 6 (27) | p= .64 |
| Activities or dealings in the community | 28 (37) | 21 (40) | 7 (32) | p= .93 |
| Leisure or recreational activities | 28 (36) | 21 (40) | 6 (27) | p= .47 |
| Dating or marital relationship | 18 (28) | 13 (30) | 5 (26) | p= .11 |
| Driving of a motor vehicle | 13 (22) | 11 (29) | 2 (11) | p= .06 |
| (Number) | 79 | 55 | 22 | |

As shown in Table 6.14, parents of children who fell above the diagnostic threshold for ADHD reported a higher mean number of impairments for their children in comparison to parents of children who fell below threshold, however this failed to reach significance ($t = -1.69$, $df.79$, $p = .095$).

Table 6. 14 Mean number of impairments by ADHD diagnoses

| Barkley's (informant version) n= 79 | Total sample (n=79) | Above threshold (n=55) | Below threshold (n=22) |
|--|------------------------|---------------------------|---------------------------|
| Mean number of impairment (sd.) | 4.45 (sd.2.7) | 4.75 (sd.2.6) | 3.59 (sd.3.03) |

$t\text{-test} = -1.69$; $p = .095$.

There was also no significant difference in mean number of impairments by two age groups as shown in Table 6.15. This finding remained after omitting the 14 to 15 year olds ($t = .905$, $df.54$, $p = .369$).

Table 6. 15 Mean number of impairments by two age groups

| Barkley's (informant version) n= 79 | Total sample (n=79) | 14 to 17 year olds (n=35) | 18 to 21 year olds (n=44) |
|--|--------------------------------|--------------------------------------|--------------------------------------|
| Mean number of impairments (sd.) | 4.45 (sd. 2.7) | 4.86 (sd.2.7) | 4.13 (sd.2.7) |

t-test= 1.17; p= .245.

Among those who still met the diagnostic criteria for ADHD, 73% had significant impairments in their *ability to function in the management of daily responsibilities* (n=40) and 71% were significantly impaired in the *ability to function in home life* (n=39). Also, parents, whose child still met diagnostic threshold, commonly reported that their child was impaired in *money management* and *functioning in educational activities* (n=36, 65% and n=36, 65% respectively).

These findings of significant impairments in daily living are compatible with previous (neuropsychological) research in ADHD that suggest that ADHD is commonly associated with executive functioning deficits (EFD's) (e.g. self-control, planning, forethought, delay of gratification, and working memory) and that these EFD's are stable over time (Biederman et al. 2007). Biederman and colleagues (2007) who followed up males (n=85) aged 9–22 years into young adulthood over a 7 year period was able to show that the majority of this sample had significant EFD's that remained stable over time (Biederman et al. 2007).

Core ADHD symptoms and associated EFD's can lead to an array of problems in the daily lives of young adults with ADHD, such as the needs identified in this study, and may include problems with saving money, buying on impulse, non-payment of bills, missing loan payments, exceeding credit card limits and not saving for retirement. The following problems were all found to be prevalent in the Milwaukee study (discussed in Chapter 2), which found that such problems were most frequent in the group whose ADHD persisted until age 27 (Barkley, 2009). Also, the UMASS study (also discussed in Chapter 2) found that 67 % of adults with ADHD compared to 15% of controls had trouble managing money (Barkley 2004).

6.5.2 Factors influencing impairment

This section considers the contribution of a range of clinical and social measures on the overall impairment of the sample, including individual ADHD symptoms, individual needs, neurotic symptoms, drug or alcohol use and problems with police. Specific ADHD symptoms that were positively associated with the overall impairment score included: “*often easily distracted by external stimuli*” ($r = .39$, $p < .001$), “*often forgetful in daily tasks*” ($r = .33$, $p = .003$) and “*often stands up in situations where sitting is expected*” ($r = .26$, $p = .023$).

Bivariate analysis also showed that specific needs domains that were positively associated with impairments included: “*food*” ($r = .26$, $p < .05$), “*self-care*” ($r = .37$, $p < .001$), “*exploitation risk*” ($r = .25$, $p = .026$), “*safety to self*” ($r = .24$, $p = .032$), “*safety to others*” ($r = .29$, $p = .010$), “*inappropriate behaviour*” ($r = .28$, $p = .011$), “*social relationships*” ($r = .29$, $p = .010$), “*transport*” ($r = .25$, $p = .030$), “*money budgeting*” ($r = .29$, $p = .009$), and “*welfare benefits*” ($r = .33$, $p = .003$). None of the other factors (e.g. neurotic symptoms, drug or alcohol use, or problems with police) were significantly associated with overall impairment.

As impairment scores appeared to be normally distributed (that is, skewness was not too far from zero at .118 and a Kolmogorov-Smirnov significance level was greater than $>.05$ at .092) all the independent variables described above that were significantly correlated with total impairment score were entered into a hierarchical multiple regression model. On the first step of the analyses, the specific inattentive and hyperactive/impulsive symptoms (i.e. “*often being easily distracted by external stimuli*”, “*often forgetful in daily activities*” and “*often stands up in situations where sitting is expected*”) were entered in to the model because inattentive and hyperactive/impulsive symptoms are known from previous research to be impairing among this group. Following this, in the second step of the model, needs with a significant association with impairment (i.e. “*food*”, “*self-care*”, “*exploitation risk*”, “*safety to self*”, “*safety to others*”, “*inappropriate behaviour*”, “*social relationships*”, “*transport*”, “*money budgeting*” and “*welfare benefits*”) were entered into the model to examine if adding these variables significantly improved the model.

Table 6.16 shows that among the ADHD symptoms only the “*easily distracted by external stimuli*” variable remained significantly associated with impairment, explaining 15% of

the variance in overall impairment. Model 2 shows that when the “*self-care*” was added to the model this significantly improved on the predictive value of Model 1 (the variable accounted for 13% of the variance in impairment). When the “*safety to others*” variable was added a further significant improvement can be seen in Model 3. In Model 4 the addition of the “*welfare benefits*” variable added a further 6% to the predictive value of the model. In total, 41% of the variance in overall impairment was accounted for by these four variables.

Table 6. 16 Regression model: correlates of overall impairment (n=76)

| Variable | Model 1 | | Model 2 | | Model 3 | | Model 4 | |
|------------------------------|---------|---------|---------|---------|---------|---------|---------|---------|
| | B | β | B | β | B | β | B | β |
| <i>ADHD symptoms</i> | | | | | | | | |
| Easily distracted | 2.29 | .391*** | 2.09 | .390** | 2.09 | .356*** | 1.93 | 3.57*** |
| Easily forgetful | | | | | | | | |
| Often stands up | | | | | | | | |
| <i>Need variables</i> | | | | | | | | |
| Safety to others | | | | | | | | |
| Food | | | | | | | | |
| Self-care | | | 2.04 | .363*** | 2.04 | .363*** | 1.71 | .340** |
| Exploitation risk | | | | | | | | |
| Safety to self | | | | | | | | |
| Safety to others | | | | | 1.68 | .250* | 1.90 | .284** |
| Inappropriate behaviour | | | | | | | | |
| Social relationships | | | | | | | | |
| Transport | | | | | | | | |
| Money budgeting | | | | | | | | |
| Welfare benefits | | | | | | | 1.68 | .255** |
| <i>R</i> | .391 | | .534 | | .588 | | .637 | |
| <i>R</i> ² | .153 | | .285 | | .346 | | .406 | |
| <i>R</i> ² change | .153*** | | .132** | | .061* | | .060* | |

Note: All regression coefficients are standardised for comparative purposes.

* $p < .05$, ** $p < .01$, *** $p < .001$.

6.6 Chapter summary

In summary, over two thirds of participants in this study still experienced ADHD symptoms (mainly inattention) that were frequent and severe enough to meet the diagnostic threshold for ADHD. The overall prevalence of self-reported psychological morbidity was 27% in this sample and this was significantly associated with ADHD, indicating that those who still meet the diagnostic criteria for ADHD are more likely to experience psychological problems in young adulthood. Illicit drug use, hazardous drinking and problems with police, however were not related to ADHD. Nevertheless, a majority of the sample had scores indicative of a drug or alcohol problem (66%) and over a quarter of the sample (26%) had been in trouble with the police in the last 12 months.

Nearly all (90%) of parents reported that their child had a significant impairment in at least one life activity and around half reported that their child had significant impairments in five life activities. The five most impairing life activities were: *management of daily responsibilities* (68%); *home life* (67%); *educational activities* (62%); *management of money* (61%); and *work or occupation* (49%). These impairments were associated with ADHD, with those who still reached diagnostic criteria for ADHD being significantly more likely to be impaired in daily activities. In particular, the specific inattentive symptom “*easily distracted by external stimuli*” was the strongest correlate of overall impairment in the sample, with other significant correlates being made up of need factors including: “*self-care*”, “*safety of others*”, and “*welfare benefits*”.

Given the high rate of persistence of troublesome ADHD symptoms and impairments found in this sample, it is clear that many young people who were diagnosed with combined ADHD in childhood may be moving into adulthood with persisting symptoms and impairments requiring continued monitoring and treatment. Difficulties in often being distracted by external stimuli are likely to impact negatively on the daily lives of young people growing into adulthood. In addition, specific needs such as “*self-care*” or “*safety of others*” may lead to further debilitation and burden.

The next chapter will focus on the needs of the sample, examining the association between needs and ADHD diagnosis. Specifically, it identifies needs of participants in a range of life

domains covered in the CANDID and seeks to show to what extent these needs were being met either by services or by informal carers (friends and family members) of the young participants.

CHAPTER 7

Results: Needs

7.1 Introduction

This chapter addresses the first research question, focusing on the needs of the participants. Specifically, it seeks to identify what the met and unmet needs of the study participants were from a range of life domains covered in the CANDID and to examine to what extent these needs were being met by services and informal carers (“services” being used here, as explained on p. 2 to denote all services in line with the use of the term in the CANDID). Among other things, this chapter demonstrates that the study participants had a range of needs which went beyond those purely related to their ADHD and that were reported as being largely unmet by services with most of the help received coming from family members and friends.

7.2 Statistical analyses

Met and unmet needs were investigated using descriptive and inferential statistics, mainly percentage distributions and means and standard deviations for categorical and continuous data respectively. T-tests were used to examine differences between those who still met the diagnostic criteria for ADHD and those who did not (as reported in the methods section as the CANDID is not normally distributed an initial investigation used Mann-Whitney U tests to examine differences in the CANDID between those who met the diagnostic threshold for ADHD and those who did not; however, as the results were similar only the results of the parametric test are reported here). Pearson’s correlations were also used to explore which factors were associated with needs in this sample (as also reported in the methods section, Spearman’s correlation were also conducted on non-normally distributed data and as the results do not differ only the non-parametric statistic is reported).

7.3 Individual Needs

As reported in Chapter 5, individual needs were assessed using the CANDID (Xenitidis 2003), an instrument which assesses needs in 25 domains of a person's life. Although need ratings were collected from both the parent and the young person, this study focuses on parent ratings of needs (analyses, not shown, show a significant correlation between the parent total number of needs and the young person's, $r=.46$, $p<.001$). Studies have suggested that parental reports are more valid than self-reports (see discussion in chapters two and eight), particularly when the individual whose needs are being assessed has a disorder which impairs their capacity for insight or the person is still an adolescent living with their parents (as was largely the case in this sample) (Barkley 1997, Henry et al. 1994) .

7.3.1 Carer ratings of needs according to CANDID

Table 7.1 shows the average number of needs reported by a parent (in most cases the mother). Parents reported that their child had an average of 5.0 needs in total (sd. 3.4) out of a possible 25 domains covered in the CANDID of which 2.6 were met and 2.5 were unmet.

Table 7.1 Mean number of Total, Met, and Unmet Needs according to Parents

| CANDID n= 82 (Potential range 0-25) | Total Needs | Met Needs | Unmet Needs |
|--|-------------|-----------|-------------|
| Mean (sd) | 5.0 (3.4) | 2.6 (2.3) | 2.5 (2.5) |

Note: Means (standard deviations).

At first glance these mean numbers of total needs give the impression that needs within this sample were low: however, when rates of individual needs (e.g. needs in individual domains) were investigated a relatively large proportion of young people were rated as having needs in specific domains.

Table 7.2 shows the distribution of needs (both met and unmet) within all 25 life domains in the CANDID as rated by parents and young persons. It shows that almost half of parents reported that their child had a need in *money management* (n=40) and in *looking after the home* (n=36). Around a third had a need in the *inappropriate behaviour* domain (n= 34) as well as in *exploitation risk* (n= 32); *self-care* (n= 32) and in the *basic education* domains (n= 24). It also shows that the top five rated met needs (by either families/friends and/or services)

were (in order): *looking after the home* (n=30, 37%), *self-care* (n=27, 33%), *eyesight/hearing* (n=18, 22%), *exploitation risk* (n=18, 22%) and *money management* (n=14, 17%).

Table 7.2 also shows that the most common unmet needs according to parents were (in order): *money management* (n= 26, 32%) and *inappropriate behaviour* (n=24, 29%), where nearly a third of young people were rated as having an unmet need. Also, over a fifth of parents reported unmet needs in *welfare benefits* (n= 17, 21 %) and *daytime activities* (n= 17, 21%). Furthermore, around a fifth of parents reported unmet needs in *social relationships* (n=16, 19%). A similar proportion of parents also expressed concern that their child had an unmet need in *basic education* (n=15, 18%) and were at *risk of exploitation* (n=14, 17%). Thus, a range of needs were identified by parents, many of which they felt were not adequately met by services and/or family and friends.

7.3.2 Differences between parent and young person's ratings of needs

Although this study focused on parent ratings of needs, significant differences between parent and young persons' ratings of needs were found. As can be seen in Table 7.2, parents reported significantly more needs than their child in ten needs domain including: *money budgeting* (49% versus 31%, $p = .005$), *inappropriate behaviour* (41% versus 20%, $p < .001$), *risk of exploitation* (39% versus 2%, $p < .001$), *self-care* (39% versus 9%, $p < .001$), *information* (27% versus 15%, $p = .03$), *food* (26% versus 7%, $p < .001$), *daytime activities* (24% versus 13%, $p < .05$), *welfare benefits* (24% versus 9%, $p = .003$), *social relationships* (23% versus 10%, $p = .011$), and *safety to self* (15% versus 4%, $p < .01$). Although ratings in the other fifteen domains were not significantly different between parents and young people, it is worth noting that young people reported more needs than their parents in five domains, namely: *other mental health problems* (34% versus 28%, $p = .33$), *eyesight/hearing* (29% versus 26%, $p = .62$), *safety to others* (23% versus 19%, $p = .47$), *general physical health* (18% versus 13%, $p = .32$), and *seizures* (2% versus 1%, $p = .56$).

Table 7.2 Prevalence of parent and young person (Y-P) ratings of needs according to the 25 life domains in the CANDID

| Type of Need CANDID n=82 | Total (met+unmet) need n (%) | | Met need n (%) | | Unmet need n (%) | |
|------------------------------|---------------------------------|-------------|-------------------|-------------|---------------------|-------------|
| | Parent ratings | Y-P ratings | Parent ratings | Y-P ratings | Parent ratings | Y-P ratings |
| Money budgeting | 40 (49) | 25 (31) | 14 (17) | 13 (16) | 26 (32) | 12 (15) |
| Looking after the home | 36 (44) | 26 (32) | 30 (37) | 20 (24) | 6 (7) | 6 (7) |
| Inappropriate behaviour | 34 (41) | 16 (20) | 10 (12) | 5 (6) | 24 (29) | 11 (13) |
| Exploitation risk | 32 (39) | 2 (2) | 18 (22) | 0 (0) | 14 (17) | 2 (2) |
| Self-care | 32 (39) | 7 (9) | 27 (33) | 5 (6) | 5 (6) | 2 (2) |
| Basic education | 24 (29) | 18 (22) | 9 (11) | 8 (10) | 15 (18) | 10 (12) |
| Other mental health problems | 23 (28) | 28 (34) | 13 (16) | 14 (17) | 10 (12) | 14 (17) |
| Information | 22 (27) | 12 (15) | 12 (15) | 5 (6) | 10 (12) | 7 (9) |
| Eyesight/ hearing | 21 (26) | 24 (29) | 18 (22) | 18 (22) | 3 (4) | 6 (7) |
| Food | 21 (26) | 6 (7) | 11 (13) | 5 (6) | 9 (11) | 1 (1) |
| Daytime activities | 20 (24) | 11 (13) | 3 (4) | 3 (4) | 17 (21) | 8 (10) |
| Welfare benefits | 20 (24) | 7 (9) | 3 (4) | 4 (5) | 17 (21) | 3 (4) |
| Social relationships | 19 (23) | 8 (10) | 3 (4) | 1 (1) | 16 (19) | 7 (9) |
| Safety to others | 16 (19) | 19 (23) | 5 (6) | 3 (4) | 11 (13) | 16 (20) |
| Communication | 15 (18) | 7 (9) | 11 (13) | 2 (2) | 4 (5) | 5 (6) |
| Safety to self | 12 (15) | 3 (4) | 9 (11) | 0 (0) | 3 (4) | 3 (4) |
| General physical health | 11 (13) | 15 (18) | 9 (11) | 13 (16) | 2 (2) | 2 (2) |
| Transport | 6 (7) | 2 (2) | 3 (4) | 2 (2) | 3 (4) | 0 (0) |
| Substance misuse | 6 (7) | 2 (2) | 1 (1) | 0 (0) | 4 (5) | 2 (2) |
| Major mental health problems | 5 (6) | 3 (4) | 2 (2) | 0 (0) | 4 (5) | 3 (4) |
| Sexual expression | 2 (2) | 2 (2) | 0 (0) | 1 (1) | 2 (2) | 1 (1) |
| Caring for someone else | 2 (2) | 2 (2) | 1 (1) | 1 (1) | 1 (1) | 1 (1) |
| Accommodation | 2 (2) | 0 (0) | 1 (1) | 0 (0) | 1 (1) | 0 (0) |
| Seizures | 1 (1) | 2 (2) | 1 (1) | 1 (1) | 0 (0) | 1 (1) |
| Mobility | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) |

7.3.3 Need ratings by ADHD diagnosis

There were no significant differences in the mean number of total needs, met and unmet needs between those who still met the diagnostic threshold for ADHD and those who did not as shown in Table 7.3. There were also no significant differences between these two groups in the percentages of individual needs identified.

Table 7.3 Mean number of total, met and unmet needs by ADHD diagnosis

| CANDID (Potential range 0-25) | Total sample (n=80) | Above threshold (n=58) | Below threshold (n=22) | t-test Sign. |
|--|--------------------------------|-----------------------------------|-----------------------------------|-------------------------|
| Met needs | 2.6 (2.3) | 2.5 (2.4) | 2.9 (2.1) | -.76 p= .45 |
| Unmet needs | 2.5 (2.5) | 2.7 (2.7) | 1.6 (1.6) | 1.82 p= .07 |
| Total needs | 5.1 (3.4) | 5.2 (3.7) | 4.5 (2.8) | .76 p= .45 |

Note: Means (standard deviations).

Differences in mean number of met, unmet and total number of needs was also investigated by age groups. Results are shown in Table 7.4 showing no significant difference between groups.

Table 7.4 Mean number of total, met and unmet needs by three age groups

| CANDID (Potential range 0-25) | 14 to 15 year olds (n=24) | 16 to 17 year olds (n=12) | 18 to 21 year olds (n=46) | F Sign |
|--|--------------------------------------|--------------------------------------|--------------------------------------|-------------------|
| Met needs | 2.6 (1.9) | 3.1 (2.6) | 2.4 (2.4) | .41 p= .67 |
| Unmet needs | 2.3 (2.4) | 2.8 (2.6) | 2.5 (2.2) | .18 p= .83 |
| Total needs | 4.9 (3.0) | 5.9 (4.6) | 4.9 (5.1) | 5.30 p= .64 |

7.3.4 Factors associated with needs

Chapter 6 showed that neurotic symptoms and impairments were significantly associated with ADHD in this sample. One would therefore expect needs also to be associated with ADHD. However, as shown in the previous section, no such significant association between needs and ADHD was found ($r = .10$, df. 80, $p = .385$). Instead, there was a strong correlation (the Spearman's correlation coefficient showed a similar result) between number of needs and number of impairment in this sample ($r = .51$, df. 79, $p < .01$).

The identification of high rates of needs in everyday functioning domains such as *money management*, *looking after the home* and *self-care* is compatible with previous (neuropsychological) research suggesting that ADHD is associated with deficits in executive functioning (e.g. problems related to self-control, planning, forethought, delay of gratification, and working memory) (Biederman et al. 2007). Deficits in executive functioning are likely to lead to an array of problems such as problems with saving money, impulse buying, non-payment of bills and loans, and exceeding credit card limits. The

following problems were all found to be particularly prevalent among those with ADHD in the Milwaukee study (discussed in Chapter 2) whose ADHD persisted until age 27 (Barkley 2009). Similarly, the UMASS study (also discussed in Chapter 2) found that 67 % of adults with ADHD compared to 15% of controls had trouble managing money (Barkley 2004).

To summarise so far, although parents reported only a mean number of five needs in this sample, a further examination of rates of needs within specific need domains revealed that a relatively large proportion of the parents identified that their child had needs in specific domains. Nearly half of young people in this sample were identified as having a need in *money management* and in *looking after the home*. Furthermore, over a third of young people were reported to have a need in *inappropriate behaviour*, *exploitation risk*, and *self-care*. Of these five top-rated needs, *self-care* was rated as a met need by the majority of parents who identified a need in this domain. The largest unmet needs, as rated by parents, were in the areas of *money management*, *inappropriate behaviour*, *daytime activities*, *welfare benefits* and *social relationships*.

Young people themselves reported more needs than their parents in the areas of *other mental health problems*, *eyesight/hearing*, *safety to others*, *general physical health* and *seizures* raising the possibility that parents were not always aware of these problems or the extent of their children's needs in these specific domains. This study surprisingly found no significant differences in needs between those who met the diagnostic threshold for ADHD and those who did not. Instead, needs were significantly associated with impairments in this sample.

7.4 Who are meeting needs?

This section focuses on those participants who were identified as having needs and will examine the extent to which these needs were met by family or friends (informal carers) and services. Where parents reported that their child had a need in a specific domain, parents were asked if their child was currently receiving any help from family or friends and/or services towards meeting this need. Where parents answered yes, they were asked to describe the type and amount of help that their child was receiving.

The next section focuses on help received towards the top five rated needs as reported by parents. However, where appropriate, a description of help received towards some of the less commonly reported needs is also given.

7.4.1 Help provided by families/friends

Overall, parents reported that they (or other family members and friends of their child) provided help in most of the domains where a need was identified. Figure 2 shows the distribution of young people who received some form and amount of help by family and/or friends (in dark grey). The table also shows (in light grey) the distribution of young people who received some help by services. It can clearly be seen that, in the majority of domains, the percentages of young people who received some help from family and/or friends towards meeting their needs were much higher than the percentages of young people receiving some help from services. Nearly all parents reported, for example, that they (or other family members or friends) provided some help towards meeting the top-five rated needs (e.g. money budgeting, looking after home, inappropriate behaviour, exploitation risk and self-care) while few reported that their child was receiving help from services in regards to meeting these needs. Examinations (not shown here) of whether help received by family or friends differed by age or by those who still met ADHD criteria revealed that there were no significant differences between groups.

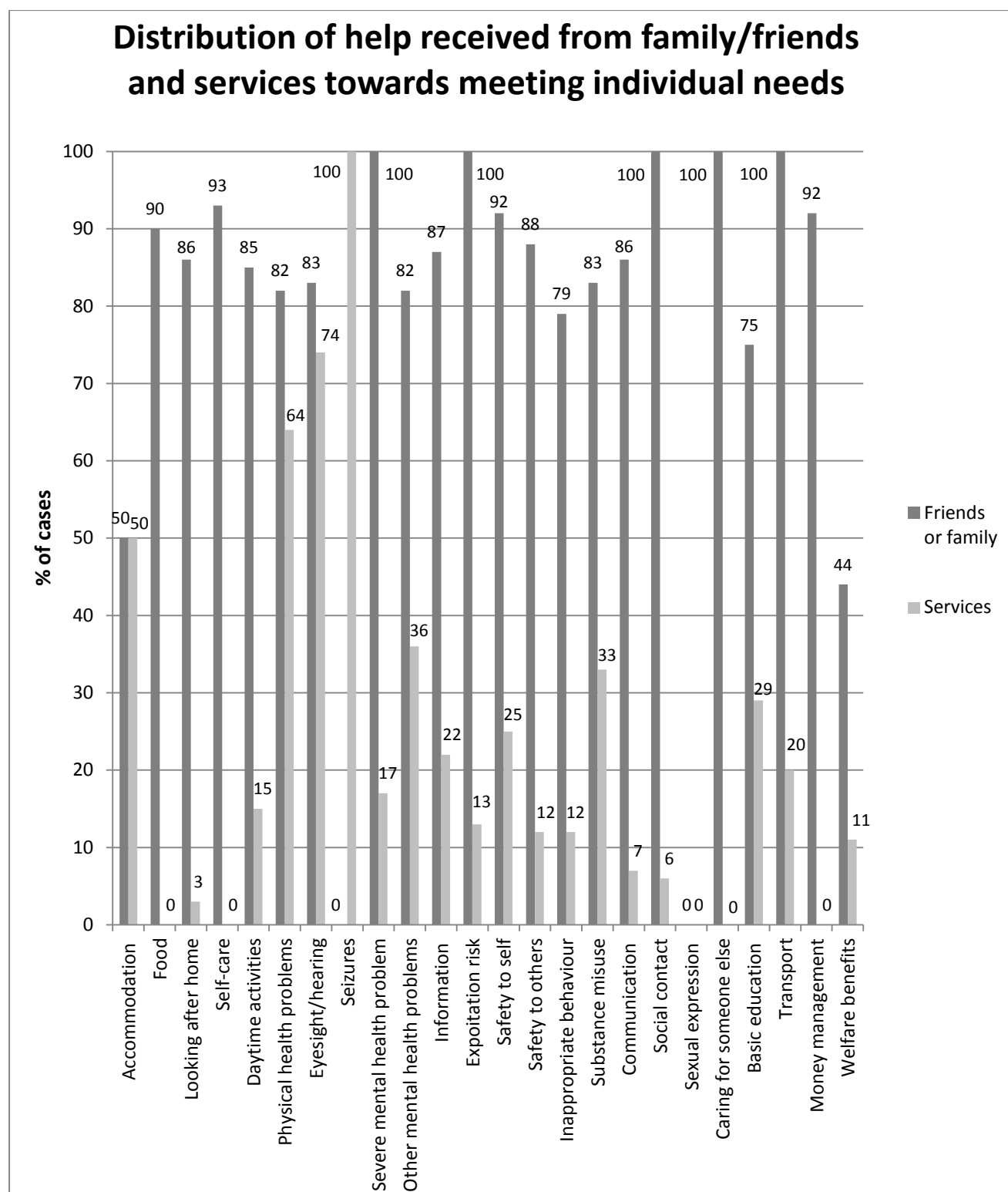


Figure 7.1 Distribution of young people with a need where some help is provided by family/friends and services to meet their needs

The type and amount of help received by young people from family or friends in the *money budgeting* domain included occasional help from family members with sorting out household bills (n=17), help with calculating the weekly budget (n=10) and receiving considerable amounts of help from parents who were in complete control of their child's finances (n=9). Four parents, however, reported that their child was not receiving any help from family or friends in this domain.

Nearly all parents (89%) with a child who had a need in the *looking after the home* domain reported that they were providing help in this domain. Most parents reported that they did all the cleaning of their child's room and washed all of their child's clothes while a small number of parents reported offering help in terms of either prompting their child to tidy up or helping their child to tidy up occasionally or at least once a week.

Among parents who reported a need in the *inappropriate behaviour* domain, the majority (n=21) reported that their child was receiving weekly supervision from friends and family with regards to their inappropriate behaviour while six parents reported that their child received informal supervision several days a week.

All parents who reported that their child was at *risk of exploitation* reported that their child was receiving some support from family and friends in regards to meeting this need. Most (n=16) described how they provided help by making sure their child knew they could contact friends or relatives if they feel unsafe. In addition, 13 parents reported that they or other family members or friends of their child were usually in contact with their child and were likely to know if their child was feeling unsafe. A small number of parents (n=3) reported that friends or relatives were in regular contact with the child and were very likely to know and provide help if their child was feeling unsafe.

Similarly, all parents who reported a need in the *self-care* domain reported offering help in this domain. This was usually in the form of prompting their child to change their clothes (n=20) or running the bath/shower and insisting on its use (n=11). One parent also reported offering daily assistance with several aspects of care, including washing their child while in the bath.

To summarise so far, parents reported providing some form of help with regards to most needs identified in the CANDID. This help was considerable when compared to the relatively low help received from services which will be discussed next.

7.4.2 Help provided by services

None of the parents in this study reported that their children were receiving help from services towards meeting needs in *money management* or *self-care* (two of the top five rated needs in this study). Moreover, few parents reported that their child was receiving help from services towards meeting their child's needs in *looking after the home* (n=1), *inappropriate behaviour* (n=3) and *exploitation risk* (n=4). For example, only 3 parents reported that their child was receiving support from services to help with their child's inappropriate behaviour. In all three cases this help was in the form of weekly checks on behaviour or more infrequent follow-up. This meant that 30 parents who reported that their child had a need in the *inappropriate behaviour* domain reported that their child was receiving no help from services in reducing their child's risk of disturbing others. In addition, only four parents reported that their child received some help from services to help reduce their risk of being exploited. In all cases, this help was in the form of having a service or professional to contact if necessary.

According to parents, the help that their children received from services was largely for physical health problems rather than for mental health problems or social needs. For example (as shown in Table 7.5), parents reported that only 12% of children with a need in the *safety to others* domain (a need reported by a quarter of young people themselves and about a fifth of parents) were currently receiving some help from services towards meeting this need. Conversely, among children with a need in the *eyesight and hearing* domain 74% were reported to be receiving help from services (usually in the form of glasses or other visual or hearing aids).

In addition to the lack of support received from services in regards to the top five rated needs, parents also reported lack of service input the less commonly reported needs. For example, the majority of young people with a need in the *basic education* domain (71%) were currently not receiving any help from services to meet this need. Indeed, only seven young people with a need in this domain were receiving some help from formal services, including two young people who were receiving professional help in filling in forms, another two who had been given advice about classes from their teachers and three who were attending adult education at the time of the interview.

Parents were also concerned over the lack of help from services in helping their child gain sufficient *information about ADHD*. 78% of parents reported that their child had not received

any help from services in gaining clear verbal or written information about ADHD and how to manage their symptoms (n=18). Of those parents (n=5) who reported that their child had received some help from services, one parent reported that their child had been given details of self-help groups, or been offered long verbal information sessions on drugs or alternative treatments. The remaining four parents reported that their child had merely received brief written or verbal information regarding ADHD and its management.

An urgent need for service input was also reported in the *communication* domain where 15 parents in total reported a need. Only one child was receiving help from services in relation to their communication difficulties in the form of communication skills training. This meant that 93% of those young people with a reported need in this domain were currently receiving no help from services in this domain.

Similarly, in the *other mental health problems* domain, where 34% of young people and 28% of parents reported a need, only one parent reported that their child was receiving specific psychological or social treatment for distress and seven parents reported that their child was either currently receiving an assessment of mental state or received occasional support from services. This meant that only 36% of young people reported as having a need (lower if young person's own ratings are taken into account), were receiving some help from services to help reduce their psychological distress with only 4% receiving specific psychological treatments.

Finally, only two of the sixteen parents (13%) who reported a need in the *safety to others* domain reported that their children were receiving help from formal services in reducing this need. As in the other mental health problems domain, this domain received more need ratings from the young people themselves than their parents, indicating that parents were not always aware of these needs in their children. Young people tended to report that they did not want their parents to know of their concerns in these two domains, as they did not wish to worry them. Therefore, at least 87% of young people reported as having a need in this domain were not receiving any help from services towards meeting this need.

As with help received from family or friends, examinations of whether or not help received by services differed by age or by whether participants still met ADHD criteria revealed no significant differences between groups.

7.5 Chapter summary

This chapter has shown that the sample had a range of needs which were unmet by services with friends and families of young people with ADHD providing most of the support. Although parents reported only a mean total number of five needs in this sample, a closer examination of individual needs revealed that a relatively large proportion of the parents identified that their child had needs in specific domains. For example, nearly half of young people in this sample were identified as having a need in *money management* and in *looking after the home* and a third of young people were reported to have a need in the inappropriate behaviour domain and to be at risk of exploitation.

Most young people in this sample with identified needs were not receiving any support from services in helping to meet these needs. This was especially apparent in the domains that were not related to the physical health of the participants but connected to the participants' mental health, everyday and social functioning. Of particular worry was the lack of support from services in the *other mental health*, *risk to other people's safety*, as these were reported as particular concerns by the young people themselves, but also the lack of service input in the *basic education*, *information about ADHD* and *communication* domains.

The next chapter will examine health service use and correlates of health service use in this sample and explore experiences of healthcare transition among this clinical group.

CHAPTER 8

Results: Health service use and healthcare transitions

8.1 Introduction

This chapter addresses the second and third research questions focusing on the sample's health service use and healthcare transition (transfer and process). Specifically, it examines the sample's current use of child and adult health services and the factors (predisposing, enabling and need) associated with health service use. Healthcare transition among the sample is thereafter explored, investigating the transfer (i.e. the move) to adult services and the processes (i.e. actions or procedures) involved in preparing young people and families for the transfer to adult care.

8.2 Statistical analyses

In order to examine health service use and healthcare transitions in this sample, descriptive statistics were used to describe the percent distribution of the sample who was still in touch with services and who were using medication for ADHD. Descriptive statistics were also used to describe experiences of healthcare transition such as help received in information transfer and coordination of transition. Next, comparisons of percentages of participants who were still in touch with health services and who were using medication were made between those who still reached the diagnostic criteria for ADHD and those who did not, and between the younger and older age groups through the use of chi-square tests. Correlates of health service use were thereafter examined using Pearson's correlations and logistic regression modelling.

Independent variables considered in the multivariate analysis for health service use included: predisposing variables (age), enabling variables (parent level of education, family place of residence and information about ADHD) and need variables (inattentive symptoms, hyperactive/impulsive symptoms, impairments, neurotic symptoms, childhood conduct disorder and carer burden). Age, and all need variables apart from childhood conduct disorder

(i.e. inattentive symptoms, hyperactive/impulsive symptoms, impairments, neurotic symptoms and carer burden) represented data on a continuous scale whereas parents' level of education, family place of residence, information about ADHD and childhood conduct disorder represented categorical data (i.e. Above GCSE level education/GCSE level education or below, Greater London/Outside Greater London, Need in information about ADHD/No need in information about ADHD and whether the young person has a childhood diagnosis of conduct disorder or not). A further categorical variable was also created for ADHD to capture those who had DIVA scores above the cut off (> 6) and those who did not (i.e. those who met diagnostic threshold and those who did not). This variable was used later in the logistic regression modelling to reduce the number of variables entered into the model and increase statistical power.

As a first step, bivariate analyses were performed with the explanatory variables and tests for multicollinearity were carried out. Multicollinearity is when two or more independent variables are highly correlated affecting the reliable assessment of the contribution of each individual variable (Petrie and Sabin, 2000). Thereafter, logistic regression was used to examine the correlates of health service use (Agresti, 1996). Results were given in the form of odds ratios (OR) for the variables alongside 95% confidence intervals (CI) and the level of significance, with odds ratios representing the effects of a given independent variable on the odds of health service use occurring. When the odds ratio is greater than one, there is a positive relationship between the independent variable and the outcome variable; when the odds ratio is below one, there is a negative association. Finally, the goodness of fit of the model was investigated using the Hosmer-Lemeshow test.

8.3 Health service use and health care transitions assessed using the Client Service Receipt Inventory

As discussed in Chapter 5, information on whether participants were still in touch with health services (whether child, adult or non-age specific services) was assessed using a modified version of the CSRI adapted for this study. The CSRI included questions on transition from child to adult services that were adapted from an existing questionnaire designed by Sloper and colleagues at the Social Policy Research Unit at York University (Sloper et al. 2006).

As part of the joint face-to-face interview, young people were asked if they were still seen by health services and whether this service was a child, adult or non-age specific service.

Participants were also asked if they had moved (or were currently planning a move) from child to adult health service, and if they had received (or were currently receiving) any support from services in regards to transition to adult health services. Participants were also asked about the nature of, and need for, support from health services and if the participants and their families were satisfied with the support they received.

8.3.1 Contact with health services

Of the 82 young participants who gave answers about health service use and healthcare transitions, just over half (n=47, 57%) reported that they were still in touch with services (as shown in Table 8.1). The majority were still seen by children's services (n=26); however, a relatively large proportion (almost a fifth) reported that they regularly attended an ADHD services without age boundaries (n=13). Only eight participants were seen by adult health services and almost half of the sample were no longer seen by any health services (n=35).

Table 8.1 Distribution of contact with health services (column %)

| Health services for ADHD | n (%) |
|--|--------------|
| In contact with health services, of which: | 47 (57) |
| <i>Children's service</i> | 26 (32) |
| <i>Adult service</i> | 8 (10) |
| <i>ADHD service for all ages</i> | 13 (16) |
| Not in contact with any health service | 35 (43) |
| Total % | 100 |
| (Number) | 82 |

8.3.2 Health service use by ADHD diagnosis

Table 8.2 shows that there was no significant difference in health service use between participants who met the diagnostic threshold for ADHD compared to those who did not ($\chi^2=1.24$; df.2, $p=.583$). Moreover, forty percent of participants who still met the diagnostic threshold for ADHD (23/58) were no longer in touch with health services due to their ADHD, indicating that they may have needs which were currently being unmet by services.

Table 8.2 Distribution of contact with health services ADHD diagnosis (column %)

| Health service use | Above threshold n (%) | Below threshold n (%) |
|------------------------------|--------------------------|--------------------------|
| Contact with services | 35 (60) | 11 (50) |
| No contact with services due | 23 (40) | 11 (50) |
| Total (%) | 100 | 100 |
| (Number) | 58 | 22 |

$\chi^2=1.24$; $p=.583$.

Furthermore, almost half (n=11) of the 23 participants who were no longer in touch with health services, despite meeting diagnostic criteria for ADHD, also had significant impairments in daily living and a drug or alcohol problem. In addition, over a quarter of these participants (n=6) had been in trouble with the police in the last year and over a third (n=8) had CIS-R scores indicative of significant psychological morbidity.

It is important to note however that DIVA questions were asked as if the participants were off medication. Given that some participants reported that they rarely came off their medication, this group of participants may have found some of the DIVA questions difficult to answer. This may have resulted in some under or over reporting of symptoms among these participants.

8.3.3 Health service use by age

Andersen (1968) suggested that factors other than (health) needs may also influence health service use and that predisposing factors, such as age, may hinder a person from accessing services. As we have seen, the literature on ADHD in adolescents who are considered too old for child and adolescent services also indicates that age is an important correlate of health service use in this sample.

As expected, participants who belonged to the older (18 to 21) age group were significantly less likely to be in touch with health services compared to those in the younger age group (n=20, 44% versus n=27, 75%, $\chi^2= 35.14$; df.2, $p<.001$) indicating that although ADHD was not associated with health service use in this sample age was (Table 8.3).

Table 8.3 Distribution of participants still being seen by services by two age groups (column %)

| Health services for ADHD | 14 to 17 year olds n (%) | 18 to 21 year old n (%) |
|----------------------------|-----------------------------|----------------------------|
| Children's service | 26 (64) | 3 (7) |
| Adult services | 0 (0) | 8 (17) |
| ADHD services for all ages | 4 (11) | 9 (20) |
| No services | 9 (25) | 26 (56) |
| Total % | 100 | 100 |
| (Number) | 36 | 46 |

$\chi^2=35.14$; $p<.001$.

A large percentage of those who still met the diagnostic threshold for ADHD (23/58, 40%) were no longer in touch with services, and those in the older group who met threshold were significantly less likely to be in contact with services than those in the younger age group who met threshold as shown in Table 8.4.

Table 8.4 Distribution of participants still being seen by services by age groups and ADHD (column %)

| Health services for ADHD | 14 to 17 year olds n (%) | | 18 to 21 year old n (%) | |
|----------------------------|-----------------------------|-----------------|----------------------------|-----------------|
| | Above threshold | Below threshold | Above threshold | Below threshold |
| Children's service | 17 (71) | 5 (50) | 3 (9) | 0 (0) |
| Adult services | 0 (0) | 0 (0) | 6 (18) | 2 (17) |
| ADHD services for all ages | 2 (8) | 2 (20) | 7 (20) | 2 (17) |
| No services | 5 (21) | 3 (30) | 18 (53) | 8 (66) |
| Total % | 100 | 100 | 100 | 100 |
| (Number) | 24 | 10 | 34 | 12 |

$\chi^2=6.06$; $p<.014$.

8.4 Medication use and associated factors

As reported in Chapter 5, medication use was recorded by asking parents to list all medications taken by their child (see "Update form" in Appendix B). Table 8.5 shows the distribution of medication use as reported by parents prior to the interview. Nearly half of parents reported that their child was not using any medication ($n=36$, 49%). Of those who reported medication use ($n=38$), most parents (79%) reported that their child was taking one

type of medication only; however, eight parents reported that their child was on two different types of medications (9%). Of these eight young people, two were using Ritalin alongside Concerta, two were using either Ritalin or Concerta together with Equasym, and two were using either Ritalin or Concerta alongside anti-depressants or Equasym. One further young person was using Strattera alongside Dexadrine. In addition, one parent reported that their child was taking four different types of medications (Ritalin, Concerta, Dixarit and Dexedrine).

Table 8.5 Prevalence of medication use of young people at the time of interview

| Medication | n (%) |
|---------------------------|--------------|
| No medication | 36 (49) |
| Medication use, of which: | 38 (51) |
| <i>Concerta</i> | 23 (31) |
| <i>Ritalin</i> | 11 (15) |
| <i>Equasym</i> | 3 (6) |
| <i>Strattera</i> | 2 (3) |
| <i>Anti-depressants</i> | 1 (1) |
| <i>Dexedrine</i> | 1 (1) |
| <i>Dixarit</i> | 1 (1) |
| Total % | 100 |
| (Number) | 74 |

8.4.1 Medication use by ADHD diagnosis

Table 8.6 shows that there was no significant association between meeting ADHD diagnostic criteria and medication use. Of the participants who were on medication and completed the DIVA (n=37), 12 (32%) no longer reached the diagnostic threshold for ADHD. This means that of the 20 participants who no longer met diagnostic criteria, just over half (n=12) were still on medication (mostly Concerta, n=7), compared to 25 of the 53 participants who still met diagnostic criteria were on medication (mostly Concerta, n=15). Thus, medication use did not differ significantly by ADHD diagnosis ($\chi^2 = .96$; df.1, $p = .328$).

Table 8.6 Distribution of medication use by ADHD diagnosis (column %)

| Medication use | Total sample n (%) | Above threshold n (%) | Below threshold n (%) |
|----------------------|-----------------------|--------------------------|--------------------------|
| Using medication | 37 (51) | 25 (47) | 12 (60) |
| Not using medication | 36 (49) | 28 (53) | 8 (40) |
| Total (%) | 100 | 100 | 100 |
| (Number) | 73 | 53 | 20 |

$\chi^2 = .96$; $p = .328$.

8.4.2 Medication use by age

Table 8.7 shows that medication use was significantly lower in the 18 to 21 year age group compared with the younger age groups ($\chi^2 = 10.02$; $df.2$, $p = .007$) with only 34% of those in this age group using some form of medication for their ADHD compared to 68% of 14 to 15 year olds and 75% of 16 to 17 year olds.

Table 8.7 Distribution of medication use by two age groups (column %)

| Medication use | Total sample n (%) | 14 to 15 year olds n (%) | 16 to 17 year olds n (%) | 18 to 21 year olds n (%) |
|----------------------|-----------------------|-----------------------------|-----------------------------|-----------------------------|
| Using medication | 38 (51) | 15 (68) | 9 (75) | 14 (34) |
| Not using medication | 37 (49) | 7 (32) | 3 (25) | 27 (66) |
| Total % | 100 | 100 | 100 | 100 |
| (number) | 75 | 22 | 12 | 41 |

$\chi^2 = 10.02$; $p = .007$.

In summary, the severity of ADHD symptoms was not related to health service use in this sample, instead participants who were younger were more likely to be in contact with health services than participants who were older. This suggests that participant's age is an important determinant of service use, indicating as Andersen suggested that other factors apart from need (health) factors are also important in influencing use of health services.

8.5 Correlates of health service use

Examining factors associated with health service use in young people with ADHD at transition is crucial to inform the development of health services for this group. In this section the influence of predisposing, enabling and need factors on health service use is examined.

As outlined in Chapter 4, variables were chosen based on theoretical grounds and previous literature with the aim of including predisposing, enabling and need variables in line with the Andersen model. It was hypothesised that age would remain a significant correlate of services even after controlling for the influence of enabling and need factors, given the significant association shown in section 8.3.3.

As a first step, the association between predisposing, enabling and need factors were considered using bivariate analyses. The results of pearson's correlations (or Point Biserial Correlations where appropriate for dichotomous independent variables) are presented in Table 8.8.

Table 8.8 Correlates of health service use: bivariate analyses (column %)

| Independent variable | r/r pb |
|--------------------------------|---------------|
| <i>Predisposing</i> | |
| Age | -.34** |
| <i>Enabling</i> | |
| Mother's education | -.02 |
| Family residence | -.11 |
| Information about ADHD | -.10 |
| <i>Need</i> | |
| Inattentive symptoms | .10 |
| Hyperactive/impulsive symptoms | .04 |
| DIVA above cut off (>6) | .10 |
| Neurotic symptoms | .15 |
| Impairments | .24* |
| Needs | .16 |
| Carer burden | .23* |
| Childhood conduct disorder | -.03 |

* $p < .05$; ** $p < .01$.

The variables with a significant bivariate relationship with health service use were: age (a negative association), impairment and carer burden (positive relationships). However, given that variables without a significant association in bivariate analyses may still contribute to service use if entered into a regression model (due to the possibility that lack of power in the

bivariate analyses may contribute to the non-significant finding) the next step was to enter all selected variables into a logistic regression model. However, given that multicollinearity is a problem in logistic regression, it was important to check for strong correlations between variables to ensure that highly correlated variables were not used in the same regression model. Checks showed that two pairs of variables were moderately correlated (i.e. correlations between 0.4 and 0.6). This included the “total number of needs” variable which was moderately correlated with impairment ($r = .51$). The needs variable was also moderately correlated with carer burden ($r = .41$). Given that needs were not significantly associated with service use in the bivariate analyses and were both impairment and carer burden were, needs were excluded from further analysis to minimise risk of multicollinearity.

In the second step, all key variables (i.e. age, mother’s education, family residence, information about ADHD, inattentive symptoms, hyperactive/impulsive symptoms, impairment, childhood conduct disorder and carer burden) were entered simultaneously into a logistic regression model to examine the relative contribution of independent variables on the outcome variable. At first, the inattentive symptoms and hyperactive/impulsive symptoms rather than the “DIVA above cut off” variable were entered along with the other key variables. This revealed that only age was a significant variable. Given that statistical power of logistic regression models is increased if there are a minimum of 10 cases per independent variable (Hosmer and Lemeshow, 1989), the least statistically and theoretically significant independent variables were then removed from the model one by one to examine what effect the removal of each variable had on the overall fit of the model (as indicated for example by a percentage increase in the model’s power and an increase in the Hosmer and Lemeshow goodness of fit test). For example, the removal of the two least statistically significant variables: family residence and childhood conduct disorder (which were also non-significant in the bivariate analysis) significantly improved the overall fit of the model. The process of removing non-significant variables was thereafter continued until the model with the best overall fit and power was achieved, leaving seven variables in the model. The final model is presented in Table 8.9.

Table 8.9 Multivariate binary logistic regression model of correlates of health service use among 14 to 21 year olds with a childhood diagnosis of combined ADHD (n=72)

| Variable | Contact with health services | No contact with health services | Odds ratios (95% CI) |
|--------------------------------|------------------------------|---------------------------------|----------------------|
| Age (years) | 16.9 (2.1) | 18.4 (2.3) | 0.62 (0.46-0.83)*** |
| High level of parent education | 17 (59) | 12 (41) | 2.27 (.67- 7.41) |
| DIVA above cut off (> 6) | 35 (61) | 22 (39) | 1.36 (.36-4.69) |
| Impairments (0-10) | 5 (2.8) | 3.7 (2.5) | 1.28 (.99-1.57) |
| Neurotic symptom score (0-49) | 8.8 (6.8) | 6.8 (5.9) | 1.06 (.96-1.16) |
| Conduct disorder | 17 (57) | 12 (43) | .94 (.29-3.04) |
| Carer burden score (0-48) | 19.7 (10.6) | 15.4 (6.8) | 1.02 (.95-1.08) |

*** $p < .001$.; Mean values (sd) or numbers (%).; 95% CI= 95% confidence interval.
For continuous predictor measures, odds ratios refer to an increase in one point on the scale.

As can be seen in Table 8.9, the only significant correlate of health service use was age (OR=0.62, 95% CI 0.46-0.83, $p < 0.001$) with a one year increase in the young person's age reducing the odds of being seen by services by 38%. Although inattentive symptoms and hyperactive/impulsive symptoms were initially entered into the model replacing these variables with the "DIVA above cut off" variable produced a better overall fit and therefore this latter variable was preferred in the final model. None of the enabling or need variables were significantly correlated with service use when entered into the logistic model.

The final model was significant when investigated using the Omnibus Test (Chi-squared value: 19.83, $df = 7$, $p = .006$). It was also significant when investigated using the Hosmer-Lemeshow goodness of fit test (Chi-squared value=7.16, $df = 8$, $p = .519$) where a significance level of $< .05$ indicates poor fit. The proportion of variance explained by the models was 0.24 using Cox and Snell R, and 0.38 using Nagelkerke R square, indicating that between 24% and 38% of the variance is explained by this model.

To examine the effect of age on service use further, the model was re-run omitting smaller age groups from the analysis. When 14 to 15 year olds were omitted from the analysis, age remained the only significant correlate of service use. Age also remained the only significant correlate of service use after 14 to 16 year olds were omitted from the analysis and the model was re-run. However, when 14 to 17 year olds were excluded from the analysis, age ceased to remain significant (i.e. no factors were significantly correlated with service use). This

indicated a cut-off point around the age of 17 health service use is likely to be significantly reduced among this group.

8.6 Healthcare transition

This section addresses the third and final research question beginning with a description of transfer from child to adult health services before shifting to consider the processes involved in preparing young people and parents for the transition to adult health services.

As part of the joint interview, families were asked if anyone had planned or talked to them about moving from child to adult services. Nearly a quarter (n=19, 23%) reported having spoken to a professional about moving to adult health services, however in some cases this conversation appeared to have been brief and informal. When asked if they had received a written transition plan, only one family reported that they had. Unfortunately, this family could not remember whether or not they had received a copy of this written plan or whether their transition plan had ever been reviewed. The age at which health services were reported to have started planning for transition ranged from 15 to 21 (mean age= 17.42, sd. 1.36, n= 19).

When asked about information that they had received (or were currently receiving) about transition and available services, young people reported significant unmet needs. Table 8.10 shows that around half of young people reported that they had not received (or were currently not receiving) enough information to help them plan for the future (47%), to show them which services are available as they grow up (51%), or to explain the transition process to them (49%).

Table 8.10 Young person reported information needs (column %)

| | Help not needed (yet) n (%) | Got/getting enough help n (%) | Needed/need more help n (%) |
|---|--------------------------------|----------------------------------|--------------------------------|
| Information to help you plan for your future (n= 76) | 27 (36) | 13 (17) | 36 (47) |
| Someone to show you which services are available as you grow up (n= 76) | 26 (34) | 11 (14) | 39 (51) |
| Someone to explain the transition process to you (n=76) | 29 (38) | 10 (13) | 37 (49) |

As participants in the 14 to 17 year old age group, and in particular those aged 14 to 15, could be expected to be more likely than the 18 to 21 year olds to report that they did not need help with transition (yet) sensitivity analyses were carried out- first omitting 14 to 15 year olds, and then 14 to 17 year olds. These results revealed no significant differences in the percentages reporting that they needed more help with regards to information to help them plan for their future, someone showing them which services are available as they grow up or someone explaining the transition process to them.

Parents were also asked about their child's information needs relating to transition and the results are shown in Table 8.11.

Table 8.11 Young person information needs according to parents (column %)

| | Help not needed (yet) n (%) | Got/getting enough help n (%) | Needed/need more help n (%) |
|--|--|--|--|
| Information for your child about future options (n= 78) | 14 (18) | 8 (10) | 56 (72) |
| Someone for your child to talk to about transition (n= 78) | 17 (22) | 6 (8) | 55 (70) |
| Someone to explain the transition process to your child (n=78) | 18 (23) | 6 (8) | 54 (69) |

Around 70% of parents reported unmet needs in their child receiving information about future options (72%), having someone to talk to about transition (70%), and having someone to explain the transition process to their child (69%). When 14 to 15 year olds and then 16 to 17 year olds were removed from the analysis, over two-thirds of parents still reported unmet needs in their child's information needs.

8.7 Co-ordinated approach to transition

Young people and parents were asked if they had had one person to support them through transition and four (5%) families stated that they had. One family reported that their transitions support person had been a nurse whilst another family reported that this had been a lead professional. Unfortunately, two families did not know their transitions support person's job title. Families reported that this support had lasted for an average of 2 years (sd.

2.67, n=4) ranging from zero to 60 months. Interestingly, only one of these families, one who could not remember the job title of their transitions support person had received a written transition plan, having received transitions support for one year. This family reported now being in contact with adult health services. The remaining three families stated that they were now being seen by an independent clinic that sees people across the lifespan.

All four families reported that their transitions support person had been proactive in making contact and that were satisfied with the number of times they had been contacted by this person.

Finally, when asked how well managed the process of moving from child to adult health services was, the majority (57%, n=12) of those who had received some help in terms of transition (n=21) reported that their transition had been poorly managed.

Table 8.12 Young person and parent perception of how well managed healthcare transition was (n=79)
(column %)

| Managed well n (%) | Managed OK n (%) | Poorly managed n (%) | Don't know n (%) | Not applicable n (%) |
|-------------------------------------|-----------------------------------|---------------------------------------|-----------------------------------|---------------------------------------|
| 2 (3) | 7 (9) | 12 (15) | 0 (0) | 58 (73) |

Instead several parents reported frustration over having had to wait over a year to receive an initial appointment at an adult service for their child to be reassessed for ADHD. During this year their child had been forced to come off their medication with no other services available to offer support despite their ongoing need for this support. These families commonly reported feeling “fed up” with services (or the lack of services) and perceived services to be lacking in understanding about ADHD in adulthood. Sadly, some reported that due to these negative perceptions of services, they were no longer interested in staying in touch with services.

Lack of support from services with regards to the transition to adult health services was reported by twenty families with a young person who still reached the diagnostic criteria for ADHD. The majority of these parents (n=16) reported having been told by child and adolescent health professionals there were no longer any services for their child as they were now adults. These parents had been told that they should expect their child to outgrow their symptoms. Nearly all of these parents reported a feeling of being “dumped” by services, at a

time when they needed support, and reported receiving insufficient help from services in helping to plan for their child's future and in showing which services were available to them in adulthood. Several parents also reported receiving a letter in the post ("out of the blue") saying that their child was no longer eligible for treatment and monitoring due to their age, with no information about alternative services to turn to for support.

As expected there was no need for the above supports among families with a young person who was seen at a service with no age boundaries. These families all reported being satisfied with the help they were receiving from their service in terms of help planning for their/their child's future and having someone to discuss their needs with.

Four out of the six participants who were over 17 and still had ADHD and were in adult health services were satisfied with how well managed the move from child to adult health services had been (two participants reporting that it was managed well, and another two reported that it was managed OK). Another two participants said it had been poorly managed.

Four of the participants had been 17 years old when health services had started planning for this move, (the other two being 18 and 22). Half of the six participants said they had received enough help with planning for the future; however four said they would have needed more help in being shown which services were available to them as they grow up. Five out of these six participants now in adult services said they would have benefitted from more help from someone explaining the transition process to them. Conversely, four parents out of these six participants who were in adult health services, said they had not received enough help about information regarding their child's future, the same four parents also reported that they needed more help from someone to talk about the transition and to explain the transition process to their child. Only one of these six young people in adult services had one person to support them through the move to adult services. Half of these young people and their parents also felt that they could have received more help from someone to talk about transition, to have someone speaking on their behalf, to have someone looking at their needs (child), to have someone looking at their needs (parent), to have someone providing individual support for them, and to have more help from someone coordinating their transition to adult services.

8.8 Person-centred approach that attends to a wide range of needs

Both young people and parents were asked if they had received enough help from someone in relation to looking at their needs and providing emotional and practical support. Table 8.13 shows that over a third of young people and parents reported unmet needs in these domains.

Table 8.13 Young person and parent transition needs (column %)

| | Help not needed yet | Getting enough help | Need more help |
|---|---------------------|---------------------|----------------|
| Someone looking at your needs (young person) (n= 69) | 12 (17) | 14 (20) | 43 (62) |
| Someone looking at your needs (parent) (n=74) | 8 (11) | 14 (19) | 52 (70) |
| Someone providing individual support for you (e.g. emotional and practical support) (n= 68) | 11 (16) | 12 (18) | 45 (66) |

When 14 and 15 year olds and then 16 and 17 year olds were removed from the analysis over two-thirds of parents and young people still reported unmet needs in relation to someone looking at their needs and someone providing individual (e.g. emotional and practical) support for them.

8.9 Chapter summary

This chapter highlighted the important role of age in influencing health service use among young people with ADHD at transition to adulthood. Despite having severe enough ADHD symptoms to meet diagnostic criteria for ADHD, older participants were far less likely to be in touch with health services. This chapter has also highlighted the need to improve healthcare transitions for this clinical group, who tended to report considerable unmet needs in receiving information about healthcare transition and having someone to talk to about their needs as well as receiving emotional and practical support. These findings will be discussed in detail in the next chapter, placing these findings in the context of current government policies and the literature.

CHAPTER 9

Discussion

9.1 Summary of key findings

This study aimed to establish the current needs and service use of a sample of young people previously diagnosed with ADHD in childhood who were now at transition from childhood to adulthood (aged 14 to 21). In addition, it examined factors associated with health service use in this group and the extent to which health services and/or family and friends were meeting the needs of this group. Moreover, it explored healthcare transition, defined as the process of moving from child to adult health services, encompassing both the transfer and the processes involved in preparing young people and families for this transition.

This study found that 73% of this clinical group continued to meet full DSM-IV diagnostic criteria for ADHD, of whom 43% met the criteria for combined type ADHD, 48% met criteria for predominantly inattentive type ADHD and 9% met criteria for the predominantly hyperactive/impulsive type ADHD. No age-related differences between the 14 to 17 year old and 18 to 21 year old age groups were found in the percentage of those who met diagnostic threshold for ADHD and those who did not. As expected, this study found high levels of impairments and comorbidities: 90% of the sample had significant impairments in at least one life activity and 27% reported psychological symptoms indicative of a neurotic comorbid disorder. This study also found that ADHD symptoms were significantly associated with both impairments and psychological symptoms.

This study also found high levels of alcohol and drug use with almost two thirds of the sample reporting drinking behaviour indicative of hazardous alcohol use and about a fifth having used Cannabis in the last month. Moreover, over a quarter of the sample reported having been in trouble with the police in the last 12 months alone. However, these outcome variables were not significantly associated with ADHD symptoms but were found to be significantly higher among older participants.

This study was the first to assess a wide range of needs in this clinical group using the CANDID. In regards to research objective (i) it identified a number of individual needs that overall were poorly met by services. Instead, families and friends of the young people were providing most of the care in order to meet the needs of this sample.

In regards to research objective (ii) this study was able to show that health service use (e.g. still being in contact with a health service) was only predicted by age, with older participants being significantly less likely to be in contact with services even when other factors were taken into account such as ADHD symptoms and psychological comorbidity. Thus, this contributes to the existing literature by highlighting the crucial role of age in influencing health service use among those with ADHD currently at transition from childhood to adulthood.

Results in relation to healthcare transition (research objective iii) showed that despite national guidelines highlighting the importance of successful transitions in healthcare and the need for improvements in this particular clinical group, only one young person had received a formal written transition plan and few had successfully transferred to adult health services (n=8). Even for those who had transferred to adult services, preparation for transfer had been rare or of poor quality in most cases (according to this sample), with the majority of young people and parents interviewed reporting a need for more information regarding available services, the transition process itself and for more consideration of their needs. In this sample, nearly half of those who still met the diagnostic criteria for ADHD were not in contact with health services despite reporting the need for formal support.

9.2 Methodological considerations

9.2.1 Choice of sample

Sampling of all 14 to 24 year olds was undertaken from the existing IMAGE research database, which originally contained 154 possible recruits within the desired age range. The 14 to 24 age range was decided on the basis that it was important to obtain information about service use and needs in a group who had recently undergone (or were currently undergoing) transition from child to adult health services. All participants had previously been recruited by referral from CAMHS in the southeast of England on the basis that they had received a clinical diagnosis of combined type ADHD (as defined in the DSM-IV manual). Their current

needs and service use were unknown. At the time of the interview participants lived in various locations in England; around half of whom resided in the Greater London area and the half who lived throughout England (from Cornwall in the South to Lincolnshire in the North East).

9.2.2 Selection bias

Given that this study used a pre-existing clinical research sample that was initially recruited from CAMHS it is important to consider the possible bias resulting from the selection of this study sample. It is possible that previous contact with mental health services in childhood may bias this sample towards presenting with high levels of psychological problems at follow-up (for example compared to those who had only been in contact with paediatricians in childhood). However, the rates of psychological comorbidity found in this study are consistent with those reported in previous studies. Similarly, it is possible to argue that given that this sample had been in contact with mental health services in childhood they could be expected to be more likely to stay in contact with services in adolescence and young adulthood. It is therefore important to bear in mind that the present study's findings regarding the relatively low levels of health service use may actually overestimate the use of health services (for example, if a group of young people with ADHD had been recruited from paediatricians instead of CAMHS).

9.2.3 Response rate

Out of a total of 154 potential recruits in the 14 to 24 age range identified in the IMAGE research database, 55% accepted the invitation to participate in the study. This is similar to recruitment rates reported in other studies that have followed-up children with ADHD (e.g. Barkley 2009, Mannuzza et al. 1998). Adult outcome studies of large samples of clinic referred children with ADHD are few in number. Only five large follow-up studies have retained 50% or more of their original clinical samples into adulthood. These include the Montreal study by Weiss, Hechtman and their colleagues (1993), the New York City study by Mannuzza, Klein and colleagues (1998), the Swedish study by Rasmussen and Gillberg (2001), the Milwaukee study by Barkley, Fischer, Smallish and Fletcher (2002) and the recent British follow-up study by Ford and colleagues (2007).

Refusals were slightly higher in the older age groups, with no 22-24 year olds agreeing to participate, however, there was no significant age difference between those who accepted the invitation to participate and those who refused (Table 5.2 in Chapter 5). The main reasons for refusals included lack of interest in participating in research projects, family breakdowns and conflicts (where parents reported having lost touch with their child making participation in a research project requiring joint and individual parallel interviews with both young person and parent difficult. The author also noted that a significant number of parents frequently reported on their own problems with depression and/or anxiety and their child's problems with police. Additionally, a few parents mentioned that their son/daughter had a current drug problem or had recently been in trouble with the law, stating this as a reason for refusing participation in the study. This may have led to an underestimate of (psychological) comorbidities in this sample as it can be hypothesised that subjects with significant psychological symptoms were less willing to participate. The author noted that a small number of those participants who initially agreed to participate but who failed to commit to the arranged interview schedule or who cancelled the interview, often reported problems with the law or with mental wellbeing. However, as shown in Table 5.2 in Chapter 5, there were few significant differences between those who accepted the invitation to participate in the study and those who did not with respect to childhood diagnoses of ADHD.

Combined, the above may have led to some recruitment bias, whereby families/young people with certain characteristics refused to participate. However, other than the factors discussed above, it was not possible to determine these factors from the brief phone calls with families. It may be that refusals among the older participants may have led to an overestimation of ADHD symptoms in this sample given the decreasing prevalence of ADHD with age. However, overall, there was a good age spread in this sample (14 to 21) with a mean age of 17, a mean age which the author felt was the ideal age to examine the transition from child to adult health services as this is the age when most young people with ADHD should be preparing for transfer to adult services.

9.2.4 The study design

This was an observational study based on face-to-face interviews and self-completion questionnaires with the young people with ADHD and their parent (usually mother). Separate rooms (usually in the participant's home) were used to ensure confidentiality during the

separate parent and young person's interviews. It was also felt that certain questions (e.g. on drug and alcohol use and problems with police) were better asked as part of a self-completion questionnaire, while the researcher was still present and could check the completed booklets to ensure responses were not missed. It is possible that the cognitive capacities (literacy, forgetfulness) and level of cooperation (defensiveness) of the patient may have led participants to rush through their responses to the drug questions (as well as some of the other questions in the self-completion questionnaire such as those relating to trouble with the police) but there was little evidence of this. Participants usually indicated if they were tired and wanted to take a break and some asked if the questions to be read out to them rather than complete these questions themselves. Unfortunately, four participants asked if they could return the questionnaire later by post to the researcher, a method that resulted in some participants sending back some unanswered questions, thus leading to missing data.

Moreover, in the case of three participants who reported having problems reading or writing, the self-completion questionnaire was fully read out to them. This was done in the same separate room where the young person's interview had been carried out so that the confidentiality of the responses could be respected. It can be argued that helping participants to complete the questionnaire will have to some extent reduced the bias associated with the inability of those with reading/writing difficulties to participate. It is difficult, however, to know to what extent administering the questionnaire compared to self-report completion will have influenced responses.

9.2.5 Validity of research instruments

Diagnostic Interview for Adults with ADHD (DIVA) and Barkley ADHD rating scale for adults

Given that all participants had received a diagnosis of ADHD in childhood, it was decided that it was not necessary to confirm this childhood diagnosis at follow-up. Thus, only current symptoms (e.g. in the previous six months) were assessed during the interviews. Symptoms were assessed using the DIVA and the Barkley ADHD rating scale for adults (Barkley and Murphy 1998, Kooij and Francken 2007). The DIVA was used to determine whether participants still met diagnostic criteria for ADHD given that the DIVA was judged to be the most valid and sensitive instrument, involving a face-to-face interview with both the young person and the parent who were interviewed together. In contrast, the Barkley rating scale has parents and young people complete rating scales separately. It was also noted that there was a

high correlation between young person and parent DIVA responses and between the DIVA and the Barkley rating scales. Therefore, both the parent and young person's reports were used to form a diagnostic opinion and a clinical judgement about ADHD symptoms at follow-up.

As noted in Chapter 5, despite the DIVA being a new diagnostic instrument for ADHD it was preferred to existing published diagnostic interviews such as the Conners' Adult ADHD Diagnostic Interview for DSM-IV (CAADID) (Epstein et al. 2001). Although the items in the two diagnostic measures are similar, the DIVA was judged to have several advantages. Most importantly, compared to the CAADID, the items were considered to be more realistic for the diagnostic assessment of ADHD in adults by the European consensus group (Kooij et al. 2010) being briefer, permitting greater freedom in responses and being used increasingly throughout Europe. It is also currently publicly available.

Traditionally, studies following children with ADHD into adulthood have based diagnosis on informant rather than self-reports. Studies have found significant disparities between informant and self-reports. For instance, a review of several studies found that the prevalence of ADHD in adulthood is at least 9 to 11 times greater in parental than in self-reports (Barkley 2009). It has been hypothesised that this disparity may be due to two factors. First, ADHD is associated with smaller prefrontal cortex areas as well as with related lower levels of brain activity levels in these regions (Tannock 1998). Damage to these areas is frequently associated with diminished self-awareness (Fuster 1997). Therefore, it is reasonable to assume that as ADHD is associated with diminished frontal lobe activity, it may also affect accurate self-appraisal (Barkley 1997). Second, studies have commonly found weak correlations among different sources of information on externalising forms of behaviour (Achenbach et al. 1987, Henry et al. 1994).

In addition, Barkley also found that parental reports of the young person with ADHD are more strongly associated with adversity in various major life activities than young person self-reports (Barkley 2009). This evidence supports the notion that parental reports are likely to have greater validity than the young person's self-reports. At the very least, the results from Barkley's follow-up study raises doubts about the practice of solely relying on the young person's self-reports to evaluate the persistence of ADHD in adulthood (Barkley 2009).

Given discrepancies between parent and young person's self-reports, an advantage of this study was its use of face-to-face diagnostic interviews which relied on responses from both informants. This may be more likely to produce reliable prevalence rates than simply relying on either self-report or informant rating scales (such as used in previous follow-up studies). However, the DIVA was originally designed as a face-to-face interview with one person at a time, and in this study both the parent and the young person were interviewed together. Although both the young person's and the parents' responses were recorded separately, clinical evaluations were difficult in some cases where there were significant disagreements between the two respondents, leaving it to the researcher to form a clinical judgement regarding significant ADHD symptoms.

The Clinical Interview Schedule-Revised (CIS-R)

As described in Chapter 5, this study used the CIS-R to assess neurotic symptoms in adolescents and young adults with ADHD. Given that this measure was designed to capture neurotic symptoms in the week prior to the interview, the short recall period may have minimised recall bias but it may also have led to an underestimation of psychological morbidity in this sample. The author noted that several participants reported having experienced significant psychological difficulties in the recent past (e.g. previous months) including suicidal tendencies. Therefore, it is likely that participants in remission at the time of the interview may not have reached criteria for significant symptoms in the measure used but may still have considered themselves (as may their parents and their doctors) to have a psychiatric disorder.

On a positive note, it was felt that young people in this study were well placed to answer questions regarding their own psychological symptoms. The author noted that several participants reported that they did not want their parents to know of their psychological symptoms and were trying to keep these a secret (in order not to worry or burden them). This was reflected in the higher number of needs reported by the young people themselves in the 'other mental health problems' domain in the CANDID measure than reported by their parents, suggesting that parents may not have been always aware of the nature or severity of their children's psychological symptoms.

Camberwell Assessment of Needs for Adults with Developmental and Intellectual Disabilities (CANDID-LD)

As discussed in Chapter 5, there is currently no “gold-standard” measure for assessing needs in young adults with ADHD. However, given that ADHD is a developmental disorder and is often associated with intellectual (learning) disabilities and mental health problems (comorbidities), it was judged that the CANDID would be the most appropriate of the available needs assessment instruments. It is a comprehensive instrument that covers a wide range of needs of people with developmental disabilities. Previous needs assessments only indirectly assessed needs of people with developmental disorders and several of them were lengthy and required specialist training for their administration. The CANDID, with its wide range of needs (25) was therefore favoured before instruments that assess fewer needs such as GAF (Global Assessment of Functioning) and DAS (Disability Assessment Schedule). As no previous studies had used the CANDID in people with ADHD, it was not known what the individual needs of this group would be and thus it was of benefit to keep the range of needs as varied as possible. Further, only a few items were considered redundant for this group (such as mobility, accommodation, food) making it a useful measure of need in this group.

This study based its analyses on parent reports, however, it also presented young people’s need ratings when these differed significantly from the parents. As discussed in Chapter 4, there is a general lack of consensus in the literature about who should assess needs. Some argue that need can only be assessed by professionals (Mooney 1986), whereas others (Bradshaw 1972) claim that individual’s assessment of their own (‘felt’ and ‘expressed’) needs is valid. As noted in Chapter 5, the combination of cognitive impairments and behavioural problems associated with ADHD (which may significantly affect young people’s ability to rate their own needs reliably), led the researcher to conclude that parents would be the best assessors for this group, particularly as the vast majority of participants were still living with their parent at the time of the interview. However, it was felt to be important to take into account the views of the young people themselves, especially when they differed considerably from that of their parents (Slade 1994).

Self-completion questionnaire

All drug and alcohol use and problems with police were only documented through self-reports. It is possible that the use of self-reports in this study to establish the presence of drug

use and antisocial activities may have led to underreporting of these activities, however self-reports may provide a more accurate picture of the frequency of these activities than would parent reports given the covert nature of drug and alcohol use and criminal activities that largely occur outside of parental supervision (O'Donnell et al. 1998).

This study investigated drug use through a series of questions adapted from the Office of National Statistics survey 'Mental health of children and young people in Great Britain, 2004' (Green et al. 2005). Questions on drug use from this survey were considered briefer and more appropriate than the equivalent questions used in the Adult Psychiatric Morbidity Survey 2007 (McManus et al. 2009). Young people were asked to self-rate the frequency and nature of drug use from a range of drugs such as Cannabis, Cocaine and Heroin (see section C in Appendix E). For each individual drug, a question was asked regarding whether the participant had ever used the drug, even if it was just once. If the young person answered yes to the first opening question two more questions followed, including: (i) at what age the young person first used the drug and (ii) whether or not the young person had used the drug in the last month. It was felt that given the sensitive nature of the questions it was best to ask these questions in a self-completion questionnaire.

Alcohol use was assessed using the AUDIT-C (Bush et al. 1998), a brief and validated three questions tool that is used to identify hazardous and harmful drinking (see Section D in Appendix E) (Bradley et al. 2007, Bradley et al. 2009). It is a modified version of the 10 question Alcohol Use Disorders Identification Test (AUDIT) instrument. This is the only screening test specifically designed for international use as it is consistent with ICD-10 definitions of alcohol dependence and harmful alcohol use. Higher scores indicate greater likelihood of hazardous and harmful drinking and may reflect greater severity of alcohol problems and dependence, as well as a greater need for more intensive treatment.

Problems with police were examined through a series of questions based on those in the background information questionnaire used in the Adult ADHD service at the Maudsley Hospital (adapted for this study). Again, as with the questions about drug and alcohol use, young people were asked these questions in a self-completion questionnaire (see section E in Appendix E). All participants were asked whether or not they had been in trouble with the police in the last 12 months. Those who answered yes were asked a brief series of questions

regarding the nature and frequency of these problems (e.g. frequency of custodial sentences, times spent in a prison cell, appearances in court).

The Zarit Carer burden Interview (ZBI)

This study assessed carer burden using the 12-item (short) version of the ZBI (Bedard et al. 2001, Zarit et al. 1980), one of the most widely used tests of caregiving burden. As discussed in Chapter 5, the shorter version was preferred as (while being briefer), it has been shown to produce results comparable to those of the full version (Bedard et al. 2001). Like the original full 22-item questionnaire, it is a self-reported measure consisting of 12 questions on three dimensions of burden: effect on the social and personal life of caregivers, psychological burden and feelings of guilt. Each question consists of a statement and the respondent is asked to state how they sometimes feel when they are taking care of the person by circling the word that best describes how often they feel that way. Although there are other measures, the 12-item ZBI has been endorsed as the best short-form version of the original (Higginson et al. 2010).

The Client Service Receipt Inventory (CSRI)

In the current study, a modified version of the CSRI was administered jointly to the young person and their parents as part of a joint face-to-face interview. This was helpful as it allowed the interviewer to probe for answers where there was disagreement or doubt about the nature or frequency of services used. In addition, as mentioned in Chapter 5, the relatively short recall period (three months in this study) should have minimised recall bias. The fact that the young person and parent were asked questions on service use and transitions together may have led to some inaccuracies as young people or parents may not have wanted to disclose all information in each other's presence. Every attempt was made to try to minimise this prior to the joint interview, by asking young people and parents beforehand (during their one to one interview with the researcher) to let the researcher know afterwards if they had used services that they did not want their parent/child to know about.

9.2.6 The statistical approach

Bivariate comparisons of respondents who fell above diagnostic threshold for ADHD to those who fell below threshold were made using two-tailed t tests for continuous variables and chi-

square tests for categorical variables. For service use outcomes, the predictive roles of age (predisposing variable), parent level of education, geographical family residence, information about ADHD (enabling variables), inattentive symptoms, hyperactive/impulsive symptoms, neurotic symptoms, impairments, needs, childhood diagnosis of conduct disorder and carer burden (need variables) were examined. Initially the univariate relationship between predictor and outcome measures were examined using Pearson's product correlations.

Due to the small numbers of specific services used in this sample and in order to limit the loss of statistical power with the appearance of 'empty cells' with multiple cross-tabulations, response categories for variables were sometimes grouped. However, the numbers even after this grouping in a few cases remained too small for reliable statistical analysis. The small sample size therefore led to a loss of information and limited the number of variables that could be entered in the model. Small numbers meant that this study was unable to show any associations that may otherwise have been present.

9.3 Principal findings

9.3.1 Persistence of ADHD

The present study found that 73% of the study sample still met DSM-IV diagnostic threshold for ADHD. This is higher than previously reported, however compares relatively well with results from previous studies that have followed-up children with ADHD of a similar age. For example, as discussed in Chapter 2, Ford and colleagues (2008) followed up a sample of children (n=115) diagnosed with ADHD or hyperkinetic disorder (according to DSM-IV or ICD-10) between the ages of 6 and 15 years and found that 60% met full DSM-IV criteria at five year follow-up (Ford et al. 2008).

However, there is current debate as to the validity of using DSM-IV diagnostic criteria for adults ADHD. In a recent meta-analysis of the prevalence of adult ADHD, Simon and colleagues (2009) concluded that the unclear validity of DSM-IV diagnostic criteria for ADHD can lead to underestimates of the prevalence of adult ADHD (Simon et al. 2009). This meta-analysis found that all twelve studies included in their review had employed DSM-IV diagnostic criteria whilst at the same time questioning its validity when applied to adults (Simon et al. 2009). Therefore, the present study's results regarding the high rate of persistence of ADHD should be considered with these issues in mind.

Nevertheless, there are various potential explanations for high levels of ADHD persistence. First, ADHD is a chronic disorder and, like other chronic conditions there may be a high level of stability over time, with affected individuals requiring ongoing monitoring and treatment. Second, inadequate treatment may be a contributing factor. Medication is known to be initially effective but treatment requirements alter over time and benefits may diminish or disappear (Swanson et al. 2008). Third, participants may not have been taking their medication or may be unable to access medications due to leaving children's services and therefore no longer receiving treatment for ADHD. Overall, the high persistence rates of ADHD in this study raise concerns regarding the long-term management of ADHD, suggesting the need for review of the condition by both clinicians and researchers.

This study is important in that it extends the results of previous follow-up studies in several critical respects. First, it identified a high level of persistence of ADHD symptoms in adolescents and young adults with a childhood diagnosis of combined type ADHD. To the author's knowledge it is the first study to follow-up children who were all diagnosed with combined type ADHD in childhood and, to the authors knowledge the only one to use face-to-face diagnostic interviews as well as self-completion (informant based and self-report) questionnaires to assess ADHD symptoms and impairments among this age group. Third, it described ADHD symptoms and impairments in this group and examined age-related differences between those who did and did not meet diagnostic threshold in adulthood.

9.3.2 Impairments and contributing factors

In addition to finding a high persistence of ADHD in this clinical group, this study also found that 90% reported significant impairments in at least one life activity. Specifically, around two thirds of parents rated their child as having a significant impairment in the management of daily responsibilities, in home life, in educational activities, and in money management. In addition, around half of parents reported that their child was impaired in work and over a third that their child was impaired in social interactions with others, in their dealings in the community, in leisure activities and in dating and driving. It is likely that some of these ratings are under-estimates as parents are more likely to rate their child as being more impaired in life activities in which they observe their child most frequently (e.g. home life and daily responsibilities). Also, reported impairment in their child's work (49%),

dating/marital relationships (28%) and driving (22%) are likely to be underestimates as not all participants were old enough to be engaging in these activities.

Although some individuals are likely to develop effective strategies and (social) skills during the transition from childhood to adulthood (to better manage their impairments and to do so more effectively), others may find this especially hard without receiving more intensive support. The findings from the present study indicate that continuing inattentive symptoms (such as being easily distractible) and high needs in the “self-care” and “safety to others” domains as well as “welfare benefits” (as defined by the CANDID) may be particularly impairing for adolescents and young adults with a childhood diagnosis of ADHD. Individuals with such impairments and comorbid psychiatric conditions especially may require a more intensive treatment programme and this may particularly be the case for specific groups such as those residing in hospital and prison settings (Young and Amarasinghe 2010).

9.3.3 Extra burden associated with ADHD: comorbidities

Psychiatric symptoms

The present study found that 27% of participants had significant psychological symptoms a week prior to the interview. In particular, depression and anxiety scores were significantly higher among those who met threshold for ADHD compared to those who did not meet diagnostic criteria indicating that not only were items like concentration difficulties, irritability and sleep problems (e.g. items often associated with ADHD) higher among this group but so were depressive and anxiety symptoms. As discussed earlier, this figure may be an under-estimate as several participants reported having had significant levels of depression or anxiety in the weeks or months prior to the interview (that is, recently but not in the last week). Seven participants had particularly high scores on the CIS-R indicative of need for urgent treatment.

Nevertheless, this study’s findings of significant psychological comorbidity in this clinical group are broadly in keeping with previous studies. Earlier studies that examined the prevalence of mood and anxiety disorders in children who have grown up with ADHD have found that girls and boys with ADHD have an elevated lifetime and 12-month prevalence of mood and anxiety disorders (Barkley and Murphy 2006, Biederman et al. 1996, Biederman et al. 2006, Lee et al. 2008, Polanczyk et al. 2007). However, some studies have not found an

association between anxiety and adult ADHD (Mannuzza et al. 1993) or have suggested that boys with ADHD are not as likely as girls with this disorder to show significant anxiety problems (Biederman et al. 2006). The present study found a significant association between current anxiety and ADHD. It was not possible to carry out statistical tests to examine gender differences in psychological symptoms due to the low number of females in this sample, however the results of the present study indicated that neurotic symptoms (depression if not anxiety) in this sample was associated with ADHD. Those with more severe ADHD symptoms were also more likely to be depressed.

However, it is important to take into account, as discussed in 9.2.2 that this study used a sample that was initially recruited from CAMHS clinics. It is likely that children with ADHD seen by CAMHS in childhood have a more severe form of ADHD with higher levels of psychological difficulties. Moreover, children with ADHD and psychological comorbidities may be more likely to engage with (mental health) services in adolescence and young adulthood than those children seen by paediatric services only (and who therefore may have lower levels of psychological comorbidities in childhood). Therefore, it is possible that the level of psychological comorbidity identified in this study is not generalizable to children seen by paediatric services in childhood.

The significant association between psychological morbidity and ADHD may also be part of the many adverse outcomes associated with adult ADHD. Epidemiologic studies suggest that, undiagnosed and/or poorly managed ADHD has a negative impact reaching beyond its primary symptoms. It has been shown to be associated with a range of adverse outcomes including school failure, teenage pregnancy, instability of employment, and early, violent, and unstable marriages (Forthofer et al. 1996, Kessler et al. 1995, Kessler et al. 1997). Such adversities during adolescence and young adulthood are likely to exacerbate any existing difficulties relating to growing up with ADHD into adulthood and may lead to an increased sense of failure and low self-worth.

Drug use, alcohol use and problems with police

In this sample of young adults with a childhood diagnosis of ADHD, many of whom, as described, continued to be symptomatic and experience significant impairment and psychological morbidity, nearly two thirds also reported hazardous levels of alcohol consumption (65%). Furthermore, 47% of the sample had used Cannabis at some point in

their lives and 22% reported having used it in the month prior to interview. This study also found that 26% had been in trouble with the police in the last 12 months, most of whom reported that such problems were due to antisocial and aggressive behaviours (e.g. speeding, criminal damage and assault), as described in detail in Chapter 6.

The finding of a high level of drug and alcohol use and problems with police are consistent with previous studies that have found that children with ADHD frequently manifest high levels of conduct problems and social aggression (Barkley 1998, Hinshaw 1987). Followed into adolescence, ADHD children, particularly those with comorbid social aggression, have been found to have a significantly elevated risk for ODD, CD, and delinquent or antisocial activities (Klein and Mannuzza 1991, Weiss and Hechtman 1993). Along with those risks come a greater likelihood of being arrested (Satterfield et al. 1994) and a higher propensity for substance experimentation, use, and abuse (Lambert and Hartsough 1998). This is particularly the case among the subset of ADHD children that also have CD in adolescence (Molina et al. 1999). As discussed in Chapters 2 and 6, the rates on drug and alcohol use and problems with police reported in this study are broadly in keeping with those found in previous studies (Kessler et al. 2006, Wilens et al. 2004). When comparing these prevalence levels to those from UK community-based studies where 23% of adolescents (11 to 16 years) report ever being in trouble with the police (Ford et al. 2003), the current rate of 25% of the sample who reported having been in trouble with the police in the last year alone, seem relatively high. The author noted that many more participants reported problems with police but not in the past year. A previous study reported police contact in the past year to be 6.6% for adolescent males (Ford et al. 2008).

Longitudinal studies have suggested that childhood ADHD independently predicts later substance use (Taylor et al. 1996), however, as shown in Chapter 6, the current study did not find an association between current ADHD symptoms and drug/alcohol use and problems with police. Given that only current ADHD symptoms were investigated it was impossible to say whether childhood ADHD symptoms were correlated with drug and alcohol use and problems with police.

Previous studies have indicated that the high prevalence of substance misuse in people with ADHD may stem from an attempt to self-medicate. For example, in their reviews, Wilens and Wilens and colleagues (Wilens 2007, Wilens et al. 2004) suggested a strong relationship

between ADHD and self-medication with drugs; between 35% and 71% of adults with alcohol dependence disorder had childhood-onset and persistent ADHD (Wilens et al. 2004, Wilens 2007). Wilens and colleagues also found that 15-25% of adults dependent on alcohol and other substances had current ADHD (Wilens et al. 1998). As discussed in Chapter 2, Mannuzza and colleagues (1989) suggested a progression from ADHD to CD and from CD to substance misuse. They also suggested that substance misuse in this group may be related to demoralisation and failure (Mannuzza et al. 1989). As in the present study, the study by Mannuzza and colleagues (1993) failed to find a significant association between adult illicit drug use and current ADHD symptoms (Mannuzza et al. 1993).

Another possible explanation for the high rates in these comorbid problems may lie in the fact that both ADHD and alcoholism tend to run in families. Researchers have pointed to common genes shared between ADHD and alcoholism (Barkley 2009) indicating that a child with ADHD with an alcoholic parent may be more likely to develop an alcohol-abuse problem. In any case, adolescent heavy alcohol and cannabis use have established risk effects on physical and mental health (MTA Cooperative Group 1999). Therefore, the findings of the present study suggest the need for intervention regarding these behaviours in adolescence and young adults with ADHD, particularly as the need for and receipt of mental health services may be particularly crucial during this time when many known mental health problems are known to begin (Patel et al. 2007). In addition, these results raise concerns over the clinical implications of untreated ADHD as studies have highlighted that the consequences of substance misuse in those with ADHD can be severe, with one study reporting that 24% of inpatients in a substance misuse treatment facility had ADHD (Schubiner et al. 2000).

Untreated ADHD and premature termination of medication for ADHD symptoms in young adulthood may mean that individuals with ADHD represent a high-risk group for drug and alcohol problems and police contact. These outcomes represent a significant cost to society as well as to the individual. Thus, any long-term clinical treatment for individuals with ADHD should include monitoring and interventions for antisocial behaviour and its impact, even at diagnostic sub-threshold levels.

Overall, these findings paint a bleak picture for those diagnosed with ADHD in childhood who are now at transition to adulthood, with a significant proportion approaching adulthood

with significant levels of psychological morbidity, impairments, drug use and hazardous alcohol drinking as well as problems with police.

9.3.4 A range of needs

This study sample included people with a range of symptoms and impairments, most of whom were still living at home with parents with varying degrees of independence, ranging from high levels of functioning, requiring only minimum support, to having significant impairments in daily activities and requiring substantial support from families to meet their needs.

Most parents reported a need in at least 5 out of the 25 domains, of which the five highest rated needs were in money management (49%), looking after the home (44%), inappropriate behaviour (41%), exploitation risk (39%), and self-care (39%). Of these, the needs in money budgeting and inappropriate behaviour were by far the highest rated unmet needs by parents (32% and 29% respectively).

As discussed in Chapter 7, the results regarding high rates of needs in *money management* and other everyday functioning domains examined, such as *looking after the home* and *self-care* in this sample is compatible with previous (neuropsychological) studies that have suggested that ADHD is associated with executive functioning deficits (e.g. in self-control, planning, forethought, delay of gratification, and working memory). Moreover, studies indicate that these executive functioning deficits are stable over time (Biederman et al. 2007). Such difficulties can lead to an array of problems in the daily lives of young adults with ADHD, such as the needs identified in this study, and may include problems such as money management, difficulties saving money, buying on impulse, non-payment of bills, missing loan payments, exceeding credit card limits and not saving for retirement (as discussed in Chapter 2).

These difficulties may partly be responsible for the high prevalence of needs found in this study not only in the *money management* domain, as identified by the CANDID, but also in the *daytime activity* domain. Parents consistently reported that their child had problems in using their time productively and tended to pursue tasks offering instant rather than long-term gratification. This may pose further risks for this group in terms of temptations to engage in

harmful behaviours and activities as they struggle with boredom and ongoing concentration difficulties.

Consistent with previous studies that have reported a high prevalence of social needs in children with ADHD (Barkley et al. 2004, Langley et al. 2010) parents in this study reported a number of such needs, including unmet needs in social contact and in inappropriate behaviours. The high needs, and in particular those unmet needs identified in the *inappropriate behaviour* domain are of concern, not only in relation to the young person's prospects of gaining employment and maintaining good relationships at work, but also in terms of their ability to establish long-term personal relationships. Children with ADHD are known to have difficulties in making and maintaining friendships in childhood, which may make it even more problematic for these young people to develop the skills necessary to establish and maintain friendships in adolescence and adulthood. Teens with ADHD are often rejected due to their age-inappropriate behaviour, and thus may be more likely to associate with other rejected and/or delinquent peers. The results of the present study indicate that a significant percentage of this clinical group are at risk of being exploited and abused, with 39% of parents reporting that their child had a need in the *risk of exploitation* domain and were subject to regular verbal abuse, and even to physical or sexual abuse. This may be because those adolescents with a history of rejection due to their age-inappropriate behaviour may frequently enter into unhealthy (sexual) relationships when what they are seeking is acceptance, approval, and love, needs which researchers suggest are vital especially during the adolescent years. It is therefore likely that some of the young people in this sample are more likely to engage in risky behaviours in order to fit in with a group. In such situations, peer pressure can impair good judgment and fuel risk-taking behaviour, drawing a teen away from the family and positive influences and make the more likely to engage in antisocial activities.

Such negative outcomes may become more likely also in the light of the high rates of needs in the CANDID's mental health domain. Young people rated themselves as having more needs in the *other mental health domain* than did their parents (28% versus 34%), often reporting that they had significant symptoms of depression and anxiety that they did not want to disclose to their parents. Moreover, young people rated higher levels of unmet needs in this domain (17%) than did their parents (12%). These results are particularly worrying as they show that not only do young people rate themselves as having high levels of needs in mental

health, many of which are unmet, but these needs may go unnoticed by their parents, therefore reducing the level of support that young people may get from home. As parents are often the key agents of help-seeking and service use in this group, and young people may opt to seek more independence from their parents during this time in their lifespan, young people may experience unnecessary distress as they struggle to cope with their symptoms on their own without formal and informal support. The young people interviewed in this study reported that they did not wish to burden their parents or worry them unnecessarily as they felt that they had done so to a significant extent in the past.

9.3.5 Help provided by family/friends and services

To the author's knowledge, this study is the first to use the CANDID to examine help provided by families/friends to young people with ADHD. The results showed that the top five rated met needs were: looking after the home (37%), self-care (33%), eyesight/hearing (22%), exploitation risk (22%) and money budgeting (17%). Such findings reflect the substantial help that is provided by families and friends rather than services (apart from the eyesight/hearing domain, in which the majority of participants received help from services). Indeed, services seemed to provide help mostly in the physical health domains, and very little input in all the other domains.

Of course needs may not only be met by formal services or informal care. Self-care has been defined as “the care taken by individuals towards their own health and wellbeing: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents” (Department of health 2005). Self-management education has been identified as having a key role to play in reducing healthcare use and in containing healthcare spending (Department of health 2005). However, the evidence supporting the impact of self-management and other chronic disease management initiatives on health service utilization is more equivocal than policy statements often imply (Roland et al. 2005). Similarly, the mechanisms underlying the purported relationship between increases in self-care activities and a reduction in utilization remain under-explored (Gately et al. 2007). However, the very nature of self-management can be problematic for a person with ADHD. Many young people may desire to manage their own symptoms and not rely on services but lack the skills required for this, including how to organize, plan and manage their daily routines. Many

parents in this study reported that their adolescent/adult child lacked the basic skills required for everyday self-care and looking after the home, often requiring daily support from family members in areas such as cooking and cleaning and keeping themselves and their living accommodation clean.

To the authors knowledge this is the first study to have compared formal and informal provision of help in this clinical group and therefore adds to the literature regarding the respective roles of family/friends and services in meeting the needs of this group. As described in Chapter 7, the needs of the young people in this study were poorly met by services, which appeared to merely provide support in physical health domains but not in other areas identified through the use of CANDID.

In the context of the current scarcity of services for adults with ADHD combined with existing problems in achieving successful transitions between child and adult health services for this group, it is hoped that the current study adds to a more comprehensive picture of the perceptions of young people and their families regarding the needs of this group. The current study identified a range of needs (unmet and met) in this sample which were currently poorly met by services. The amount of help provided by families in this study was substantial in comparison to that provided by services which raises questions as to the welfare of not only those with ADHD but also the support providers (whose caring roles may go overlooked and who may frequently face negative perceptions about ADHD from the media and the public). The more that can be learnt about parents and young people's perceptions concerning their needs, the more we can inform social policy makers about how to design future services that are better able to meet the needs of this group.

9.3.6 Correlates of health service use

This study found that despite the fact that a large majority continued to meet diagnostic criteria for ADHD, 43% of this sample were no longer in contact with any health services. This finding may be explained in several ways. First, as discussed in Chapter 2, and as also reported by participants in this sample, few adult services currently exist for adults with ADHD. Several participants interviewed for this study explained that they were not aware of any services that would be able to see them as they were now 16 or 18 (i.e. implying that they were too old for existing services). Second, this study's findings indicate that parents too were often unaware of any suitable services and that the lack of information on appropriate

services meant that they did not know which services to access once CAMHS were no longer available (despite often recognising a need for continuing support). Third, attitudinal barriers were also reported by parents and young people during interviews stating that their doctors appeared to think that ADHD was not a real disorder and that their children were just naughty and would grow out of it. The answers to the transitions questions in the joint interview booklet used in this study also often conveyed the parents' belief that the problem would eventually get better by itself, and that it was 'better' to try to cope without outside help from doctors or medicines, or that they were fed up with ADHD/ADHD services due to poor input in the past. Some young people also reported that they wanted to accept themselves as they are and not try to change things through medication or interventions, feeling this would mean they could "stay true to their real character". Others reported thinking that treatment takes too much time, is inconvenient or that it would not do any good. Fourth, some parents mentioned that the medicines for ADHD were expensive and that they could not afford them now that their child was an adult.

The rates of health service use in this study are broadly consistent with previous studies that have examined service use for mental health problems. These studies have shown that despite the considerable impairment and distress associated with most mental disorders (e.g. depression and anxiety disorders), and despite the availability of effective treatments, most individuals with prevalent disorders are not currently treated (Kessler et al. 2006). For example, even when there was a perceived need, only 59% of adults with past-year mood, anxiety, or substance abuse disorders who took part in the National Comorbidity Survey in America had sought mental health treatment (Mojtabai et al. 2002). Most individuals with lifetime disorders eventually seek treatment, but substantial delays are common (Kessler et al. 1998, Wang et al. 2004, Wang et al. 2005). Younger age at onset, less severe disorders, and older age at assessment in epidemiologic surveys have all been found to be associated with greater lifetime delays in help seeking (Kessler et al. 1998, Wang et al. 2004).

Such findings suggest a need for appropriate mental health services. However, as discussed in Chapter 4, some individuals who meet diagnostic criteria for a disorder may not experience sufficient impairment or distress to perceive a need for treatment (Kessler et al. 1998, Wang et al. 2004). Conversely, individuals may experience severe distress, perceive a need and seek services in the absence of diagnosable disorders (Katz et al. 1997). Others who are symptomatic and impaired with a diagnosable disorder may perceive a need, but nevertheless

do not seek mental health treatment (“perceived” or “subjective” unmet need) (Katz et al. 1997, Mojtabai et al. 2002) pointing to the complexity in trying to unravel correlates of mental health service use.

Influence from predisposing variables

This study found that age was the best correlate of health service use. Controlling for enabling and need variables, the results indicated that the older participants were significantly less likely to have used health services even after ADHD symptoms and other need variables were taken into account. This worryingly indicates that, irrespective of how severe your ADHD symptoms are, it is much less likely that you will be in contact with services as you grow into adulthood.

Influence of need/health variables

Perhaps the most worrying finding was that severity of ADHD did not predict health service use in this sample. This is in stark contrast to several other studies which have found that the more severe a person’s ADHD symptoms, the more likely they are to be in touch with services. One possible reason for this is the issue of problem-recognition (and therefore subsequent help-seeking) among this clinical group given that inattentive symptoms rather than hyperactive/impulsive symptoms are more likely to persist into adulthood and these symptoms may appear less disruptive to observers (such as parents). Moreover, parents reported a shift in their help-seeking role which may have led to a decrease in service use in this sample. As described in Chapter 8, several parents reported that it was no longer their responsibility or “legal role” (or even right) to interfere in the child’s service use as they were now considered “adults”. Moreover, the majority of parents of young people who had left CAMHS reported that adult health services no longer encouraged them to be actively engaged in their child’s treatment or service use (some were even discouraged from attending their child’s clinical appointments). This shift in the parents’ role from being an active agent in their child’s service use to taking on a less forceful role may help to explain (at least in part) why young adults are less likely to use services. Having relied on their parents (usually mothers) to take an active role in the management and treatment of their disorder, many young adults may have found this change difficult, leading to many of them stopping using services. Again, the cognitive impairments associated with ADHD may also make it difficult for young adults to

self-manage their own symptoms and to remember to organise such things as appointments and requests for repeat prescriptions.

It may also be that health services were not sought despite recognising significant ADHD symptoms (e.g. behaviours may be perceived as abnormal but nevertheless be considered acceptable for a given person). The decision to not seek health services may also indicate that parents and young people have an alternative explanatory model of their child's behaviour and do not see it as a medical issue (that is, to be dealt with by formal services). Telford and colleagues (2006) pointed out that discontinuing treatment in people with ADHD may reflect a decision on the part of the individual or family to shift the condition of ADHD to the background and allowing the person to experience a degree of wellness, and so thus to appear more "normal" (Telford et al. 2006). Eschewing treatment for ADHD may enable families and teens to gain some measure of control and feelings of wellness, in spite of continued ADHD symptoms. Many teens desire to portray themselves positively and the focus on ADHD and "illness" may not allow them to do this

However, the results of the present study also imply that another reason for not using a health service (apart from being considered too old), may be that one is unsure where to go for help and lacking information regarding the persistence and treatment of ADHD. The families appeared to have little information relating to healthcare transition and reported very little help from services in accessing this information when preparing to leave child and adolescent services. This lack of transition planning and support will be discussed next.

9.3.7 Healthcare transitions

This study found that the majority of those aged 16 to 21 (who were likely to be or have been at transition) had unmet needs in relation to transition planning, information regarding transition and adult services as well as in which services were available when they no longer qualified for CAMHS. The results of this study suggest that health services for those who continue to be symptomatic for ADHD and who can no longer stay in child health services, are extremely limited. Moreover, formal transition planning while the young person is still in child and adolescent services was extremely rare, with one family reporting receiving a written transition plan. In addition, around two-thirds of parents and young people reported that they needed more support from services in having someone looking at their needs and provide more emotional and practical support. Several families, including the young people themselves,

reported that they had felt “dumped” by services, with some reporting receiving a letter in the post saying they would no longer be able to be seen by their current service due to their age (without any offer of alternative support). Others reported that they had been informed by their child psychiatrist or paediatrician that they would need to go back to their GP if they had any future problems in order to get a referral to see an adult psychiatrist. Parents commonly reported that this was “off-putting” as many had previously struggled to get a referral to an “appropriate” service, a process they did not wish to go through again. The findings of the present study therefore indicate that despite the recommendations set out in several government and NHS guidelines regarding transition for this clinical group (as discussed in Chapter 3) (Department of Health 2004, Department of Health 2008, National Institute for Clinical Excellence 2008), much more needs to be done to improve healthcare for young people with ADHD at transition to adulthood.

9.4 Limitations

The present study has some limitations that should be taken into account when interpreting the results. As only those with childhood IQs over 70 were included, this study’s findings may not be generalizable to those with intellectual disabilities. This is important as previous studies have shown that adults with borderline and mild Intellectual Disability (ID) may have more needs and more severe ADHD symptoms in adulthood when compared to those with ADHD but no ID (Xenitidis et al. 2010). Therefore, the present findings should be interpreted as being more relevant for young people with childhood ADHD but without an ID. Likewise, as this study involved participants who were mostly males and who were all from a Caucasian background the effects of gender and ethnicity on health service use could not be examined. As previous studies have indicated, there are significant variations in health service use by gender and ethnicity among young people with ADHD (Bussing et al. 2003c, Eiraldi et al. 2006, Leslie and Wolraich 2007). Therefore, this study’s findings may not be generalizable to other groups with childhood ADHD: females and those from ethnic minority groups.

A further limitation was that information regarding problems with police and services use was restricted to participant self-reports. It was not possible to confirm such self-reports with objective data which may have resulted in an under or over-reporting of outcome variables. However, this seems unlikely given that a short recall period was used only information

about current contact with services was used in this thesis. A more likely possibility is that this method may have resulted in an underestimate of police problems as it may be that some participants chose not to disclose information regarding problems with police because they were concerned that others would find out.

9.5 Priorities for future research

As well as improving our knowledge about needs and health service use among young people with a childhood diagnosis of ADHD at transition to young adulthood, this study also poses questions and priorities for future studies.

First, as it is important that health services reflect the needs of patients that they serve, future studies should examine whether or not these findings can also be extended to females, those with intellectual disabilities and those from ethnic minority groups. It is unclear whether the findings of this study adequately represent the needs and service use of these groups.

Second, both parent/partner and young person's perspectives of needs are important in informing and addressing the development of services and the two could be compared over time to monitor how effectively services are meeting the needs of this group. Conducting needs assessments over time could help inform clinical practice and commissioning regarding staff recruitment and training as well as measures necessary for meeting the needs of this group.

Third, whilst highlighting the significant impact of age on health service use in this group, this study has only scratched the surface as to why age is important in determining service use. Future studies may wish to explore what may mediate age in this group. Help-seeking is complex and may involve several factors early in the help-seeking process. For example, beliefs and attitudes surrounding ADHD, ADHD treatments and health service use may be important factors through which age affects use of health services. In particular, researchers may wish to explore how young people and parents view their past experiences with services and treatments and whether they believe that these experiences influence their current decisions to seek help. A deeper understanding of why young adults with ADHD aged 18 to 21 years may be less inclined to seek help from services is crucial for improving services.

Fourth, in relation to correlates of health service use within this group, future studies may wish to investigate the relative contribution that other predisposing factors such as gender and ethnicity have on service use and healthcare transitions among adolescents and young adults with a childhood diagnosis of ADHD and may also benefit from including those with a wide range of intellectual abilities in addition to their ADHD diagnosis.

Last, to further improve our knowledge of healthcare transitions among this group, more research is needed to examine the processes and clinical practice that lead to improved clinical outcomes and patient experiences for this group. Establishing the methods and procedures that help to engage adolescents and young adults with ADHD with services is a crucial public health issue and task for researchers and clinicians alike. It may lead to more effective and cost-effective outcomes for this group as well as more positive outcomes for the larger society. For this reason, clinicians working with adolescents and young adults with ADHD should consider incorporating intervention research that examines the impact of clinical and policy developments in healthcare transition.

9.6 Recommendations for policy and practice

This study's findings have several implications for policy and practice relating to (mental) health service support at transition for young people with ADHD. This section draws out the key recommendations for healthcare professionals, policy makers and commissioners addressing this study's findings relating to (i) needs, (ii) correlates of health service use, and (iii) healthcare transition among this group.

9.6.1 Addressing the needs of adolescents and young adults with ADHD

To address the needs of adolescents and young adults with ADHD healthcare professionals, commissioners and policy-makers all need to recognise that ADHD often continues into adulthood and is associated with significant impairments and psychological comorbidity. As this study shows, a range of health and social problems are prevalent among young people with a childhood diagnosis of ADHD. To address these issues it is important to think creatively about the most (cost) effective ways to identify and meet the needs of this group at transition. Given changes expected in the way mental health and social care services are commissioned in England (as outlined in the Coalition Government's Health and Social Care Bill), health professionals, and GPs in particular, will have greater powers to address the

needs of this group at a local level. ADHD services for children and adolescents vary considerably between regions (e.g. CAMHS, paediatrics, availability of shared care). It is essential that commissioners take local resources into account when designing transition services in order that realistic and deliverable provisions can be made within services that are often required to work at high capacity within strict budgets.

First, to improve the mental health of not only young people with ADHD but society at large, it is essential that the long-term health, social and economic consequences of untreated ADHD are addressed and prevented. NICE has already highlighted the significant costs to society that result from the problems associated with ADHD, such as the impairments and psychological comorbidities found in this study (National Institute for Clinical Excellence 2008). For example, ADHD results in decreased function, comorbidities and unemployment and has been shown to lead to marital problems, substance abuse, accidents, and criminal offences (Barkley, 2009). These complications pose serious challenges to clinicians and commissioners who need to work closely with local authorities and agencies to address the range of needs associated with this group and prevent serious harm both to the young person and society at large. Although the costs involved in providing a comprehensive treatment package (i.e. both drug treatment and psychological interventions) may appear significant, these may still be cost-effective in the long term if they serve to reduce future costs. When making decisions about the allocation of limited resources commissioners should consider the high efficacy of the interventions used to treat adult ADHD and the significant benefits to society of treatments, particularly for prisoners and those who have left prison (Lichtenstein et al. 2012). It may be that choosing to fund these interventions may give better value for money than choosing to fund treatment for some of the other mental health conditions, for which interventions may not be as effective (Adamou 2010).

Second, health professionals, commissioners and policy makers all need to recognise that adolescents and young adults have specific healthcare needs that deserve to be adequately addressed in UK health services (Kennedy 2010, Gleeson and Turner 2012). In contrast to many other European countries, such as Australia, New Zealand, Canada and the USA, adolescent health is not seen as a distinct speciality in the UK (Gleeson and Turner 2012). Given that some studies in UK in children's hospital (McDonagh et al. 2006), among specialist trainees in paediatrics (Dieppe et al. 2008) and among healthcare professionals involved with transitional care in a speciality (McDonagh et al. 2004) have reported a lack of

training in adolescent health as a barrier to the delivery of transitional care adequate training in this area may be of benefit to healthcare professionals (Dieppe et al. 2008, McDonagh et al. 2006). It is important that professionals that care for adolescents and young adults with ADHD are kept abreast of evidence-based, up-to-date recommendations about the management of this disorder as part of their continuing professional development. In addition, any professionals coming into contact with people with ADHD should address any misconceptions about adult ADHD, drug treatment for adults, treatment efficacy and the validity of adult ADHD. Such training in the diagnosis and treatment of ADHD has recently been endorsed by the Royal College of Psychiatry and is being regularly delivered across the UK by the United Kingdom Adult ADHD Network (UKAAN). This needs to be extended to other mental health practitioners (Young and Amarasinghe 2010).

Third, to further improve healthcare transitions for young people with ADHD health services need to be young person friendly, flexible and local. Child practitioners (CAMHS practitioners and paediatricians) should foster engagement with AMHS through open discussion and psycho-education about ADHD, the benefits of evidenced based psychological and pharmacological treatments where appropriate, the risks of disengagement and endeavour to minimise stigma associated with referral to AMHS. Moreover, clinicians must develop an open-minded approach toward young people's needs. The needs that are of most concern to young people may be different to those identified by healthcare professionals. Therefore, it is important that young people's own perceptions of needs are listened to and addressed. Indeed, there is evidence to suggest that providing young people with a sense that their current needs and experiences are being heard may make them less likely to disengage from health services (Young and Amarasinghe 2010). Consequently, both child and adolescent services should be more targeted toward providing psycho-educational material to limit this exodus. The needs of adolescents and young adults as they move into adulthood should therefore be seen of upmost importance by using a person-centred approach and by listening to the young person as opposed to just talking to their parents.

The interviews carried out with both the young person and the parent in this study suggested that young people would value person-centred care that attends to a broader range of needs (i.e. not just their medical needs). Treatments should also include interventions for comorbid symptoms. Direct psychological treatments should be considered that target a range of areas including social skills, interpersonal relationship problems (with peers and family), problem

solving, self-control, listening skills and dealing with and expressing feelings. To deliver this, clinicians require skills in psychosocial interviewing which may be aided by the use of a psychosocial screening tool such as HEADS (Goldenring and Rosen 2004). Furthermore, there is some evidence that skills in motivational interviewing (Brown and Wissow 2009, Channon et al. 2007) and brief intervention strategies (Milne and Towns 2007) can be beneficial in addressing health risk behaviours as well as non-adherence. Depending on the issues raised by the young person and the skills of the clinician, options may include involving different providers from social care, mental health, education and employment, to offer further support to young people. Simply giving the young person the opportunity to discuss these issues in the consultation can be beneficial (Brown and Wissow 2009).

Fourth, improving young people's self-management skills is in line with the Coalition Government's emphasis on personalisation in healthcare which includes giving patients more choice and control over how they budget their own healthcare. This requires health and social care providers to encourage and enable people using services to exercise more choice and control over their own lives (self-management and help-seeking). This, in turn, requires that local authority and mental health commissioners ensure that people have access to information and advice to make good decisions about their care and support. This poses serious challenges for people with ADHD, who as this study has shown, are likely to have significant difficulties in managing their daily responsibilities, including, for example, their money. Clinicians will need to think of creative ways to support young people and families in how to best manage their healthcare budgets. One way may be to offer workshops or psycho-educational material on money management to support and make families feel more prepared for this change.

Fifth, in order to address the needs of this clinical group health services will need to be flexible. As children mature the mode and agent of intervention are likely to shift to reflect the developmental needs and circumstances of the individual. Most importantly, clinicians should ensure that across all age groups the goals and methods of treatment are both meaningful and motivating for the individual (Young and Amarasinghe 2010). Thus, treatment should be modified at key developmental transitions using developmentally sensitive behavioural strategies in order to reflect the behaviours that are most impaired at the time while taking into account the individual's level of understanding (Young and Amarasinghe 2010). In addition, clinicians should offer young people choice in treatment and

the way that treatments are offered. Young people have expressed an interest in communication via email or text (Dovey-Pearce et al. 2005) and clinicians may wish to identify those most likely to benefit and prefer to access interventions from home through the use of screening measures (Dovey-Pearce et al, 2005). For example, “Sweet Talk” is a novel intervention that has been used to support young people with diabetes between clinic visits using text messages sent to a mobile phone (Franklin et al. 2006, Franklin et al. 2008) and a similar service could be trialled in young people with ADHD. Furthermore, the use of web based interventions has been shown to increase self-management skills (Mulvaney et al. 2010), enhance education and awareness of community resources (Weissberg-Benchell et al. 2007), act as a novel means of assessing knowledge (Benchimol et al. 2011), assist with information transfer (Wolfstadt et al. 2010) and enhance peer interaction (Holmes-Walker et al. 2007).

Sixth, continuity of care is likely to be best achieved by providing care in local services. Primary care and community-based services are likely to be less stigmatising, more accessible, and no costlier than hospital based care (there is also evidence that such services are more greatly appreciated by patients) (Henderson et al. 1999, Ruggeri et al. 2006). Health services that are local are also more likely to work more effectively with a variety of local agencies and services, for example with other local NHS services, law-enforcement agencies, prison services and voluntary services. Specialist, more expensive, resources can be directed towards those most in need and most likely to benefit from intensive care.

Seventh, the findings of this study suggest that families of adolescents and young adults with ADHD are critical to meeting the needs of this group. The multiple ways in which families offer support and help this group need to be recognised by health professionals and policy makers. In addition, given the high familiarity of ADHD (with approximately 20% of parents of children with ADHD having ADHD themselves) many parents of adolescents and young adults with ADHD are likely to require support as well (Faraone et al. 2000a). Thus, clinicians should also consider the needs of families and partners of young adults with ADHD and the various ways that they may be supported in providing help. For instance, in highlighting to carers their potential eligibility for carers’ allowance. Being a parent with a young person with ADHD and potentially having ADHD themselves may mean that their own ability to model organisational skills for their children is limited (e.g. completing healthcare forms, replying to letters from health teams, remembering to take medication).

Likewise, familial ADHD may further challenge families who, faced with unclear pathways for transition to adult care, have to navigate through a quagmire of healthcare bureaucracy to find appropriate adult healthcare for their adolescent. Both child and adult teams should be mindful of the impact of possible parental ADHD on the transition process and provide clear structured support to families in transition (Young et al. 2011b).

Last, it is important to recognise that parents are also making the transition from parenting a dependent child to an independent adult. Getting the balance right is challenging for parents of any teenager, let alone those with the added burden of chronic illness and/or disability. A major aspect of this for the parent of a young person with a chronic condition is the gradual move from primary responsibility for health management to enabling the young person to self-care. Parents and carers need to be prepared and facilitated to aid their children's gradually increasing independence and autonomy with their ADHD and its treatment. Referring child and receiving adult/GP teams should be mindful of possible parental ADHD and needs for support and manage this appropriately. A recent study of transition in diabetes services in the UK identified the involvement of parents in the transition process as key in supporting management continuity. Ensuring that parents continue to have opportunities to be involved is important, particularly when the young person moves to being seen without their parent (Allen et al. 2010). Some studies have found transition planning for parents, similar to that available for young persons to be of value (McDonagh et al. 2006).

9.6.2 Addressing barriers to care

Although it appears that barriers to care for children with ADHD have reduced in recent years (Sayal 2010), the results from the present study suggest that much more needs to be done to improve access to care for young adults with ADHD. Despite policy and research developments over recent years advocating an increase in the availability of services for adults with ADHD, the findings from this study indicate that age remains a significant barrier to accessing treatments. It is important that commissioners and healthcare professionals recognise the Equality Act 2010 which now includes provisions enabling a ban on age discrimination against adults in the provision of services and public functions. Health services need to be able to benefit affected adolescents and young adults and should not just be targeted to children with ADHD. Hence, the decision to refer or offer services should not be based on age or other predisposing factors. Rather measures need to be put into place to

ensure that enquiries about symptoms and needs are made and that methods are developed that ensure that severity plays a stronger role in decisions about referral and health service provision at all ages.

Among clinicians, an improved knowledge of barriers to accessing health services and treatments is a necessary part of developing needs-led services. Clinicians should be aware that young adults may face discrimination due to their age. Therefore, many adults with ADHD have gone unrecognised and untreated despite available evidence-based treatments. It is crucial that clinicians address this issue and base their clinical decisions around need rather than predisposing factors such as age.

Within the conceptual framework of Andersen's behavioural model, both enabling factors, such as service availability and health promotion (not considered in the present study but which nevertheless are important), and need factors (such as perceptions of ADHD, needs and impairments) may be modified to increase access to health services and use of health services among young people with ADHD. Information for both parents and young people that promotes mental health during the transitions from childhood to adulthood could contribute to efforts to improve and implement appropriate and cost-effective services for this group. This could involve the provision of accessible information through various types of media, schools and healthcare. As the findings of this study show, many families still lack appropriate knowledge about ADHD and what treatments and services are available.

It is unclear how the new commissioning system will influence access to and availability of health services for young adults with ADHD. These new rules will hopefully mean that commissioners can address the current difficulties surrounding healthcare transition and lack of services for adults with ADHD by designing services and care pathways around need rather than age.

The results from the present study indicate that medication use is significantly lower in people aged 18 to 21 who remain symptomatic for ADHD in comparison to those aged 14 to 17. This is especially worrying considering that a recent study found that young people's own experience of stimulant medication is generally positive and that they felt that it reduced their disruptive behaviour and improved their peer relationships (Singh et al. 2010a). It should be noted that many young people in the present study commented that they no longer saw the need for medication use or that they wished that it would become possible for them to cope

with ADHD without the help of medication. For instance, several young people interviewed in this study had taken themselves off medication, simply because they wanted to see if they could cope without it, questioning the need for life-long medication. They also saw less need for medication since leaving school and reported that their lives were now less demanding (especially if they were not working or studying) and therefore they did not need medication. In contrast, parents commonly viewed coming off medication as immature and harmful believing that this would significantly impair their functioning in various life activities.

From a public health perspective, public education and stigma campaigns could help to target those most in need of services but least likely to use services, for example those with severe symptoms and impairments who believe that treatments do not work. It is important that this public education includes information on the likely benefits of treating and managing problems associated with ADHD now rather than later. This is because receiving appropriate treatment and/or interventions is likely to reduce complications in young adulthood such as marital problems, substance abuse, accidents, and criminal offenses. Interventions to increase treatment utilisation among individuals who have persistent ADHD might beneficially include public health initiatives to foster more favourable attitudes toward utilisation of mental health services and increase knowledge of where to obtain treatment. These may also include more support to young people and their families to prepare them for the future and for the transition to adulthood. Families in this study also frequently described how media and health professionals continue to misrepresent and misunderstand ADHD as a childhood disorder that is largely caused by bad parenting rather than neurobiology. This highlights the urgent need for responsible reporting in the popular media, which continues to provide contradictory and sensationalist accounts about childhood disorders and medication use which are only likely to hinder service use in this group. Access to information and advice in non-threatening situations could enable young people and their families to discuss concerns and needs and to seek appropriate treatments.

One way to tackle these issues is to develop screening measures to identify those most in need. The main aim of these measures would be to identify severity of symptoms, impairments and needs and desire to use services. However, careful consideration should be given to developing alternative means of support to those adolescents and young adults who have symptoms and needs but who do not want to use services.

9.6.3 Improving healthcare transitions

The finding that more than two thirds of this sample continued to meet full ADHD diagnostic criteria at transition indicates that many young people with a childhood diagnosis of ADHD will require transition to adult healthcare. Although few young people in the present study had transferred to adult health services, most of those who had reported that their transitions had been of poor quality. To prevent more serious and long-lasting problems developing into adulthood it is crucial that commissioners and healthcare providers safeguard this group by ensuring that the quality of services they receive during transition to adulthood does not suffer. Commissioners should ensure that effective transition services lead to reduced numbers of (i) young people lost to services during the transitional years and (ii) untreated illness and poor outcomes. This should, in turn, lead to reduced morbidity, thus reducing the demand on mainstream services.

Several tools exist for commissioners to enable them to improve transitional healthcare for this group. These include: (i) the Joint Strategic Needs Assessment (JSNA) which can be used in line with the government's mental health strategy "No Health without Mental Health" to ensure that, together with public health colleagues, the needs of young people with ADHD at transition from adolescence to young adulthood are identified, (ii) the NMH DU/NCSS Transitions Action Planning tool (<http://www.chimat.org.uk/self-assessmenttools>), a web-based self-assessment tool for commissioners and services to self-assess key aspects of transition and identify particular gaps and actions and (iii) "Paths to Personalisation", a good practice guide produced by The National Mental Health Development Unit on how to make personalisation a reality for people with mental health needs.

It is almost certainly the case that there is no single 'ideal' template for ADHD transition services. Instead, local commissioners and health providers will need to design their services based on local needs and resources (Bolea et al. 2012). However, certain general practice recommendations can be made that cut across different patterns of service delivery and which should be taken into account when setting up such services.

First, CAMHS/paediatrics and adult services should develop a more co-ordinated approach to transition in line with NICE recommendations to ensure the needs of the young people at transition will be appropriately met (National Institute for Clinical Excellence, 2008). Formal joint working arrangements should be put in place to address structural and procedural

difficulties arising from the interface of CAMHS and AMHS and the differences in approach arising from cultural differences arising from child and adult services. This may require that child and adult clinicians meet, to set up, implement and review robust transition arrangements. These meetings may also involve discussion and collaboration with educational and/or occupational agencies. In addition, full information about the young person's paediatric/CAMHS care should be available to the adult teams, including a detailed clinical transition report.

Second, clear transition protocols need to be developed and reviewed jointly by CAMHS/paediatric services, AMHS, primary care and commissioners to ensure that optimal transition is viewed as a process that is planned in advance by both referring and receiving services. These protocols should be developed with service users' involvement to ensure they meet the needs of the young people who will use them. This is because the overriding conclusion of qualitative/descriptive studies on healthcare transition is that prior to the healthcare transfer, many young people want to meet members of the adult service and report benefitting from meeting them (Miles et al. 2004, Tuchman et al. 2008, Zack et al. 2003). However, meetings with members of adult services need to be carefully considered as a room full of professionals, some of whom are strangers, can be daunting for anyone, least of all a young person (conversely, a series of one to one consultations may also be equally unappealing) (Allen et al. 2010). It is also essential that protocols contain specific guidance for implementation at ground level and not only vague prescriptions and that these protocols are made available to all clinical teams so that they can be effectively translated into practice.

Third, it is essential that psycho-educational material is given to both young people and their parents to ensure that they have access to comprehensive, impartial and appropriately written information regarding ADHD and transition. These could be given as part of the transition protocol or as a separate document. The findings of this study indicate that many young people with ADHD at transition lack information about ADHD and its management. Many expressed a disinterest in obtaining such information (viewing it as their parents' responsibility). Thus, to increase the chances of young people gaining more information about ways that they can manage their own symptoms and problems, and access advice and support, such information should also be developed in a media format that is easily accessible to young people, e.g. through the use of phone applications and internet sites.

Fourth, to aid joint working between child and adult teams, commissioners may wish to consider various staffing interventions. For example, they may consider the possible benefits of a dedicated professional whose role spans paediatric and adult services thereby performing a valuable integrating function. A recent systematic review found benefit in a member of the healthcare team having such a role (Crowley et al. 2011). “Transitional care coordinators” could have a range of skills, for example they could: focus solely on assisting young people in navigating the healthcare system by arranging appointments and sending reminders (Van Walleggem et al. 2008), provide holistic care as a healthcare professional (Betz and Redcay 2005) or work with young people as a professional in this area, such as a youth worker. It may be that in the UK, specialist nurses are ideally placed to fulfil this role as they are held in high regard by young people and their carers and are identified as providing good management continuity in comparison to the medical team (Allen et al. 2010).

Fifth, even if transitional co-ordinators are not employed it is essential that both child and adult teams (and primary care) have clear expectations of what procedures they are likely to undertake during the transition process. Gleeson and Turner (2012) recommended a preparation phase in paediatric care; a transfer phase from paediatric to adult services; and an engagement phase in adult services (Gleeson and Turner 2012). For example, child clinicians would be more involved in ensuring that the timing of the initiation of the transition process is based on an initial needs assessment. They would also have the duty of referring young people appropriately, based on the outcomes of the needs assessment. Conversely, after transfer a comprehensive needs assessment should be carried out by adult clinicians that include an assessment of any comorbid conditions. Should such a comorbid disorder be found a referral for assessment or treatment/support of such associated difficulties should be made. Adult services should also ensure that the outcomes of the transition process are reviewed to inform future practice.

Sixth, child services (CAMHS or paediatric services) should ensure that young people with ADHD are reassessed at school leaving age and that this assessment includes an assessment of readiness for transfer. The timing of the transfer of care to adult services should be assessed on an individual basis, using measures of readiness, for example, being seen independently from their parents, other evidence of self-advocacy, and condition and management knowledge. Methods of assessing the young person’s readiness to being seen independently from their parents and other evidence of self-advocacy, and condition and

management knowledge, have gained more attention recently (Fredericks et al. 2010, McPherson et al. 2009, Sawicki et al. 2011, van Staa et al. 2011, Williams et al. 2010). Such tools may potentially be useful in transition planning from both clinical and research perspectives. It is important that young people are informed of the outcome of this assessment and transitioned according to need, e.g. to GP services, adult community mental health teams (community, learning disability or forensic as appropriate), specialist adult ADHD teams, or adult physical health teams where required. In addition, all adult/GP teams receiving referrals should be jointly informed of the outcome of this initial assessment.

Seventh, clinicians and commissioners need to address the problems currently faced in relation to referral pathways to support a smooth transition between CAMHS or paediatric services and adult services. Currently, paediatricians and child mental health professionals face barriers when referring to AMHS due to the accepting team's referral criteria. These criteria typically require the presence of "enduring mental health problems" which means that if an adult mental health service believes that neurodevelopmental disorders fall outside of this criterion then many individuals with ADHD, and other neurodevelopmental disorders such as autism and mild to moderate learning disability, are likely to fall through the care net (Young et al. 2011b). Young people with ADHD whose needs have been met by paediatric services, in particular, may find that there is no equivalent service for adults. Paediatricians need more aids for transfer, especially as the "Care Programme Arrangements" (CPA) that are available and used as aids for transfer in CAMHS for young people age 16 or over are not available in paediatric services. Therefore, a planned assessment of need with the young person and their parent and a clearly documented plan of action is recommended.

Last, a three tiered model of care for transitioning for young people with ADHD could prove helpful whereby the pathway is determined for each individual based on the level of complexity and need (Taylor et al. 2010). Taylor and colleagues (2010) suggested that those with good symptom control could be managed by general practitioners (GPs) alone, with facilitated access back to specialist services available if required. The second tier would be for young people with more complex needs and involve a shared-care protocol between GPs and specialist nurses. In this model, specialist nurses would take a pivotal role as the clinical lead in providing support for young people and their families to facilitate transition, acting as a "skilled bridge" between GPs and adult mental health services. The third tier is for those with ongoing mental health needs (e.g. comorbidities such as depression, anxiety, Asperger's

Syndrome) who require specialist services for assessment and intervention, and who would be managed by specialist care pathways within adult mental health. From a case note review of their own caseload, Taylor and colleagues suggested that 5% of their patients could be discharged rather than referred on, 29% could be referred back to the GP, 29% would require shared care between a specialist nurse and the GP, and 36% would require AMHS (30% general adult, 6% learning disability) (Taylor et al. 2010). However, given that the rates of comorbid mental health problems were considerably lower in Taylor and colleagues (2010) paediatric clinical sample than would be expected from the literature it could be argued that the proportion of patients requiring follow up by mental health services may be higher in other clinical populations. In any case, the proposed model is likely to still apply to both paediatric and mental health services given that both patients with very different profiles with respect to severity of core ADHD symptoms, prevalence of psychiatric and physical comorbidities, associated social and educational problems and treatment.

Extending the role of primary care in the treatment of young people at transition with ADHD may result in significant improvements for this group. Historically, the role of GPs in managing ADHD in children and adolescents has been restricted to shared care of prescribing with specialists in secondary care; the latter monitoring continuing care whilst GPs write the prescriptions (Young et al. 2011b). However, given that transition patients will have often received many years of specialist care by CAMHS or paediatric services and the GP will have access to significant documentation of this care. Likewise, many GPs will already have been prescribing for this group, with specialist monitoring provided by paediatric/CAMHS teams. Therefore, it may be that GPs are well placed to manage a proportion of transitioning patients whose ADHD is stable on treatment, much as they manage cases of anxiety or depression, provided that they are provided with relevant training and adequate support. Likewise, specialist nurses can make a very important and helpful contribution to the management of adults with ADHD, as long as they are well trained in both ADHD and adult mental health problems and are given adequate support. (Young et al. 2011b).

However, it will still be necessary for a considerable proportion of patients to have their care managed by general AMHS, with a proportion of patients also referred to specialist adult ADHD services as required (Young et al. 2011b). Drawing on their clinical experience of working with children and adolescents with ADHD Young and colleagues (2011) suggested that one potential model of care for this group would comprise a single care pathway, with

agreed protocols for assessing and monitoring core ADHD symptoms, comorbid mental health, physical problems, common associated difficulties (e.g. relationship problems and occupational/academic problems), overall impairment, and managing both pharmacological and non-pharmacological treatments. Within this care pathway there would be different levels of care (e.g. GP only, GP + specialist nurse, AMHS, specialist adult ADHD services) with agreed protocols to assist decisions about who is managed at each level *and* how and when patients should move between levels with as little disruption to care as possible. Transition from child and adolescent services to this pathway should also be clearly described with the possibility of transition occurring at different ages/stages and in different ways as required (Young et al. 2011b). Best practice may therefore be for local services to commission and implement a single, simple, and clear transition pathway that, regardless of whether the young person comes from a paediatric or CAMHS team, provides needs-assessment and transition as required to adult or GP services.

9.7 Summary

This study shows that ADHD is related to significant impairments and psychological difficulties which may pose particular challenges during the transition to adulthood and that add to the burden for families, young people and society. At transition, adolescents and young adults with ADHD represent a vulnerable group who are likely to have continuing needs that are currently poorly met by health services. Key to improving transitional care are the healthcare professionals themselves who would benefit from training in adolescent healthcare as part of their continuing professional development and who require adequate resources to carry out their work. Without wider organisational support transitional healthcare is unlikely to become fully integrated into health services. Changes need to be made in policy, funding and training to enable the flexibility and continuity needed to put the young person at the centre of care (Kennedy 2010).

With significant changes expected in the way that health and social care is delivered and commissioned in the UK strong clinical leadership is paramount. Locally, it falls to willing and able clinicians to negotiate a deal for young people and transitional care. The new GP-led commissioning provides real opportunities to improve care for adolescents and young adults with ADHD. The provision of (mental) health service for young people at transition with ADHD requires considerable negotiation, planning, and support from commissioners and

clinicians. However, bearing in mind the significant costs to the individual, family and society that are associated with untreated ADHD it would seem that investing in transition is likely to result in long-standing gains.

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Appendices

Appendix A Ethics Committee approval letter



2008/089 **National Research Ethics Service**

**The Joint South London and Maudsley and the Institute of Psychiatry NHS
Research Ethics Committee**

South London REC Office (2)
1st Floor, Camberwell Building
94 Denmark Hill
London
SE5 8RS

Telephone: 020 3299 5033

08 January 2009

Professor Philip Asherson
Professor of Molecular Psychiatry & Honorary Consultant Psychiatrist
MRC SGDP Centre
Institute of Psychiatry
De Crespigny Park
London SE5 8AF

Dear Professor Asherson

Full title of study: Service use and needs among those with ADHD during
the transitional years from adolescence to young
adulthood
REC reference number: 08/H0807/68

Thank you for your letter of 17 December 2008, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements.

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document | Version | Date |
|---|------------|------------------|
| ZARIT Caregiver Burden Interview | | |
| SF-12 (Health Survey) | | |
| Questionnaire: AUDIT | | |
| Questionnaire: Drug use | | |
| Questionnaire: Current behaviour scale - self report | | |
| Questionnaire: CANDID Research version | | |
| Questionnaire: Service use and needs among adolescents/young adults with ADHD - Patient version | 1 | |
| Interview Schedules/Topic Guides | CIS-R | |
| Peer Review | SLAM | 10 April 2007 |
| Covering Letter | | 18 July 2008 |
| Protocol | 1.0(3) | 17 July 2008 |
| Investigator CV | P Asherson | |
| Application | 1 | 25 July 2008 |
| Response to Request for Further Information | 1 | 17 December 2008 |
| Participant Self Completion Booklet | 2 | 15 December 2008 |
| Joint Interview Booklet | 2 | 15 December 2008 |
| Invitation letter respondent (living alone) | 2 | 17 December 2008 |
| Invitation letter respondent (partner) | 2 | 17 December 2008 |
| Update form for parents | 2 | 08 December 2008 |
| Participant Consent Form: Partner | 2 | 12 December 2008 |
| Participant Consent Form: Respondent | 2 | 08 December 2008 |
| Participant Consent Form: Parent | 2 | 08 December 2008 |
| Participant Information Sheet: Partner | 2 | 08 December 2008 |
| Participant Information Sheet: Respondent | 2 | 08 December 2008 |
| Participant Information Sheet: Parent | 2 | 08 December 2008 |
| Letter of invitation to participant: Parents | | 17 December 2008 |
| Investigator CV | | |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views

known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

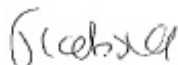
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/H0807/68

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



pp
Mr T Eaton
Chair

Email: ethics.office@iop.kcl.ac.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Mrs. Gill Lambert, SLAM R&D

Appendix B Recruitment documentation



*Institute of Psychiatry
Social, Genetic and Developmental
Psychiatry Centre and Department of
Child and Adolescent Psychiatry*

*Prof. Philip Asherson
Dr Karen Glaser
Mrs Hanna Eklund
Miss Dee Howley
Mr James Findon*

*Email: Hanna.Eklund@kcl.ac.uk
Phone: 07812 487 226, 02078485359
Email: Deidre.Howley@kcl.ac.uk
Phone: 02078485359
Email: James.Findon@kcl.ac.uk
Phone: 02078485359*

Date

Address

Greeting

Invitation Letter Parents **20.10.10 version 5.0**

You and your family took part in the International Multi-Centre ADHD Genetics (IMAGE) project. We would like to thank you and your family for your earlier participation in this project

We have now obtained funding for a new study - to find out what happens to young adults who were diagnosed with ADHD as children or adolescents. This research is important because we know that ADHD continues into adult life in around 65% of cases and is no longer a problem in the other 35%, yet we know very little about the service use and needs (if any) of people diagnosed with ADHD when they were children or adolescents.

We are therefore inviting families who took part in the IMAGE project to take part in this new study (a letter about this study has also been sent to your son/daughter). The project is part of a 5-year programme to develop more effective services and treatments for young adults with ADHD that has been funded by the National Institute of Health Research (NIHR); who are the major funding body for National Health Service (NHS) research in the UK. The project brings together a team of researchers from the Institute of Psychiatry, King's College London (KCL) and the London School of Economics (LSE).

Background to the study

This new study came about because there are currently very limited resources to help people who have persistent problems with ADHD as young adults. Although we know that many young people no longer need help or treatment for ADHD, this is not always the case, and it is currently very difficult for people with continued problems to get the help they need. In some cases people may feel that they no longer need help once they reach adolescence or adulthood but may find that they still struggle at work or in their social relationships due to the persistence of some problems related to ADHD.

We therefore wish to find out more about the way that people diagnosed with ADHD are coping as young adults - whether the problem with ADHD has resolved or is being successfully managed, or whether they are still finding that some of the problems have continued and are affecting their ability to cope as adults. Where there are continued problems we wish to know whether they are receiving

First interview

the support of treatment that they need for any problems related to ADHD. We are also interested in finding out how the ADHD may impact on the well-being of others (such as parents or partners).

What does the project involve?

The main part of the research involves three interviews with you and your son/daughter at yearly intervals. The focus of the questionnaires will be on your son/daughter's use of health and social services and level of need. With your son's/daughter's permission, we will ask you to complete a similar questionnaire about ADHD that you completed when you first took part in the IMAGE study. If there are continued problems with ADHD (or problems related to the ADHD) that involve you in supporting your son/daughter in any way, we would like to ask you about the impact of their condition on your own well-being, employment situation and health. If your son/daughter is living away from home with a partner or close friend we will seek permission from your son/daughter to ask their partner to complete questions about them instead of you.

We will also ask your other children who do not have ADHD and who previously participated in IMAGE to fill in brief questionnaires about their current behaviour. In addition, it would be helpful if you could complete a brief rating scale about their behaviour as well. Sibling participation is not essential for this study; however, it would help us to understand more about changes in people with ADHD and their siblings as they grow older.

How can I find out more about this study?

Please find enclosed an UPDATE FORM, which we would greatly appreciate if you could fill in and return to us. This will enable us to keep you informed about progress with this and other projects that are related to the IMAGE project.

If your son/daughter has moved from the family home and is living either alone or with a partner or close friend, we would like to contact them to invite them to take part in this study. Currently, we hold no details for your son/daughter and will not contact them unless permission is given for us to do so. We have enclosed an information sheet for you and your son/daughter, which explains more about the study.

A member of our research team will be in touch shortly to discuss the project. If you would like to take part they will arrange a home visit (or a visit to our centre if you prefer) to conduct the interviews. If you do not wish to be contacted by us please return the UPDATE FORM in the freepost envelope provided. If you have any enquiries in the meanwhile, please do not hesitate to contact us.

Many thanks for taking the time to read this letter.

Yours sincerely,

Prof Philip Asherson, Professor in Molecular Psychiatry
Dr Karen Glaser, Senior Lecturer in Gerontology
Hanna Eklund, NIHR researcher and PhD student
Deirdre Howley, NIHR Researcher

Enc.



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Phone: 02078485359
Email: James.Findon@kcl.ac.uk
Phone: 02078485359*

Date

Address

Greeting,

Invitation Letter Respondent
20.10.10 version 4.0

You and your family took part in the International Multi-Centre ADHD Genetics (IMAGE) project. We would like to thank your earlier participation in this project.

We have now obtained funding for a new study - to find out what happens to young adults who were diagnosed with ADHD as children or adolescents. This research is important because we know that ADHD continues into adult life in around 65% of cases and is no longer a problem in the other 35%, yet we know very little about the service use and needs (if any) of people diagnosed with ADHD when they were children or adolescents.

We are therefore inviting people who took part in the IMAGE project to take part in this new study. The project is part of a 5-year programme to develop more effective services and treatments for young adults with ADHD that has been funded by the National Institute of Health Research (NIHR); who are the major funding body for National Health Service (NHS) research in the UK. The project brings together a team of researchers from the Institute of Psychiatry, Kings College London (KCL) and the London School of Economics (LSE).

Background to the study

This new study came about because there are currently very limited resources to help people who have persistent problems with ADHD as young adults. Although we know that many young people no longer need help or treatment for ADHD, this is not always the case, and it is currently very difficult for people with continued problems to get the help they need. In some cases people feel they no longer need help during adolescence, but find that they still struggle at work or in their social relationships due to the persistence of some problems related to ADHD.

We therefore wish to find out more about the way that people diagnosed with ADHD when they were younger, are coping as young adults - whether the problem with ADHD has resolved or is being successfully managed, or whether some problems related to ADHD have continued. Where there are continued problems we wish to know whether young people are receiving the support and treatment that they need for any problems related to the ADHD. We are also interested in finding out how the ADHD may impact on the well-being of others (such as parents or partners).

What does the project involve?

The main part of the project involves three interviews with you and your parent (or partner if you prefer) at yearly intervals. The focus of the questionnaire for you will be on your use of health and social services and level of need (if any). In addition to completing the same questions about your level of service use and level of need (if any) one of your parents (or partner if you prefer) will also

be asked about the impact of your condition on their own employment situation and health, if you are still experiencing any problems related to ADHD.

A member of our research team will contact you shortly to discuss the project. If you would like to participate they will arrange a home visit (or a visit to our centre if you prefer) to conduct the interviews. Please find enclosed an information sheet for you and your parent about this project. If you have any enquiries in the meanwhile, please do not hesitate to contact us.

Yours sincerely,

Dr Philip Asherson, Professor in Molecular Psychiatry
Dr Karen Glaser, Senior Lecturer in Gerontology
Hanna Eklund, NIHR PhD student and researcher
Dee Howley, NIHR researcher
Enc.



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Social, Genetic and Developmental Psychiatry
Centre and Department of Child and
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*Email: Hanna.Eklund@kcl.ac.uk
Phone: 07812 487 226
Email: Deirdre.Howley@kcl.ac.uk
Phone: 02078485359
Email: James.Findon@kcl.ac.uk
Phone: 02078485359*

Parent Information Sheet 20.10.10 version 5.0

Information sheet for the study of service use and needs among adolescents/young adults with ADHD

**Please read the following information before you decide
whether to participate in this research**

You and your son/daughter are being invited to take part in this research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. **Your participation in this study is completely voluntary.**

Thank you for reading this.

What is the purpose of the study?

The aim of this study is to investigate service use and needs during the transitional years from adolescence to young adulthood and associated outcomes among those who have been diagnosed with ADHD. This will involve questionnaire based interviews at yearly intervals over a three year period with your son/daughter.

- ADHD has largely been regarded as childhood disorder despite growing evidence that symptoms continue into adulthood. Thus, few studies into the service use and needs of adolescents and young adults with these disorders have been conducted. Moreover, despite the transition to adult services being an important element of high quality service provision for an increasing number of young people with ADHD there has been little investigation of this issue.

Why have you been chosen?

We are inviting people who were part of the IMAGE (International Multi-Centre ADHD Gene) project to take part in this study. We will be examining patterns of service use and needs and will look at how these change during the transitional years from adolescence to young adulthood. We are also interested in investigating the impact of these changes on your and your child's well-being.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are still free to stop your participation at any time and to have research data relating to you withdrawn without giving

any reason. Please note that once analysis of the anonymised data is under way it will not be possible to have data withdrawn.

What will I have to do if I take part?

At a time convenient for you and your son/daughter (with your consent), we will arrange to interview you both at home (or at the Institute of Psychiatry if you prefer, your travel expenses will be reimbursed). The interviews will take approximately one hour each (including a brief joint interview at the end). Because it is sometimes difficult for young people to judge their own levels of attention and activity (as well as levels of service use and need) it is important for us to ask someone who knows your son or daughter well, such as yourself, to complete some of the same questions about them but also to answer some questions about yourself.

To ensure confidentiality we will ask to carry out two separate interviews (preferably in two different rooms) with you and your son/daughter. It would be useful to carry out these interviews at the same time in order to save time and then to do a joint interview with both you and your son/daughter to ask a few more questions at the end. The interview with your son/daughter will involve answering some questions about their daily life (such as employment, study etc) and about their level of need. We will also ask questions about any other psychological symptoms they may have. In addition, we will ask him/her to complete a self-completion questionnaire. This self-completion questionnaire consists of three parts: (i) questions about their attention and activity levels over the last 6-months; (ii) a brief series of questions about their moods, and (iii) a series of questions on alcohol and drug use, and any police contact.

We will also ask you to complete the same questions about your son/daughter's behaviour in the past 6-months and about their level of needs as best as you can (from your perspective). In addition, we would like to ask you a few questions about your own background, current employment situation, and health, particularly about the impact that caring for your son/daughter with ADHD has had on your health and well-being. Following these two interviews we would like to ask you to answer a few questions together with your son/daughter about the services your son/daughter has used in the past few months and about your son/daughter's experiences of transitioning from child to adult services (if your son/daughter has done this).

As a thank you for your time, your son/daughter will be given a £20 gift voucher at the first interview.

In addition, we would also like to ask your other children who participated in IMAGE, but who were not diagnosed with ADHD, to fill in a brief self-completion questionnaire. It would also be helpful if you could fill in a brief rating-scale about their behaviour. These questionnaires will be left with you and you can complete them at your convenience. Sibling participation is not essential, so you can still choose to take part in this study without their involvement.

What are the possible benefits of taking part?

Taking part in research projects is often a rewarding and interesting experience. The information we get from the study will help to better inform service use during the transitional years from adolescence to young adulthood among those with ADHD.

What are the possible disadvantages and risks of taking part?

There are no foreseeable risks in taking part in the study. The main disadvantage to taking part in the study is that you and your son/daughter will be donating around an hour or so of your time every year for three years to take part. It is possible that you may find answering some of the questions distressing. This is unlikely but if it were to occur the interview could be terminated at any time.

Confidentiality

All personal information is regarded as strictly confidential and will be held securely until the research is completed. Your participation is voluntary. If you change your mind, you are free to stop your participation and to have your data withdrawn without giving any reason. All data for analysis will be anonymised.

What if something goes wrong?

We don't envisage any major risks associated with taking part in this study. In the event of you or your son/daughter suffering any adverse effects as a consequence compensation will be made through the King's College London 'No Fault' Compensation Scheme. This scheme includes payment of damages or compensations in respect of any claim made by research participants for bodily injury arising out of participation in any clinical trial.

Consent

If in the unlikely event that, after giving informed consent, either you or your son/daughter were to lose capacity once the study had begun, participation would be terminated immediately and any identifiable data would be either anonymised or disposed of.

What will happen to the results of the research study?

This research will be analysed by researchers at the Institute of Psychiatry, King's College London (KCL), and the London School of Economics (LSE). The results will be used to inform health service provision and the development of services for ADHD. A report of the study findings can be sent to you once the research has been completed.

Who is organising and funding the research?

The National Institute for Health Research (NIHR) funds this research. This is government funding aimed at improving clinical diagnosis, treatment and health provision in the United Kingdom.

Who has reviewed the study?

The study has been subject to review by expert referees for the National Institute for Health Research. The NHS Research Ethics Committee has granted ethical approval.

Future research at King's:

We would like to be able to contact you with details of further research projects concerning young people with ADHD at the Institute of Psychiatry in the future. However, you are under no obligation to agree to be contacted about future participation.

Contact for further information:

Please ask if there is anything you do not understand or if you would like more information.

Hanna Eklund, Brain Maturation, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF

Tel: 0207 848 5368 Mob: 07812 487 226
E-mail: Hanna.Eklund@kcl.ac.uk

Dee Howley, Brain Maturation, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF
E-mail Deirdre.Howley@kcl.ac.uk

James Findon, Brain Maturation, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF
Tel: 0207 848 5359
E-mail: James.Findon@kcl.ac.uk

Dr Karen Glaser, King's College London, The Strand, London, WC2R 2LS
Tel: 020 7848 2554
E-mail: Karen.Glaser@kcl.ac.uk

Professor Philip Asherson, MRC Social Genetic and Developmental Psychiatry, The Institute of Psychiatry, De Crespigny Park, Denmark Hill London SE5 8AF.
Tel: 020 7848 0078
E-mail: Philip.Asherson@kcl.ac.uk



Institute of Psychiatry
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Phone: 07812 487 226, 0207 8485359
Email: Deidre.Howley@kcl.ac.uk
Phone: 02078485359
Email: James.Findon@kcl.ac.uk
Phone: 02078485359*

Respondent Information Sheet **20.10.10 version 5.0**

Information sheet for the study of the service use and needs among adolescents/young adults with ADHD

Please read the following information before you decide whether to participate in this research

You are being invited to take part in this research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. **Your participation in this study is completely voluntary.**

Thank you for reading this.

What is the purpose of the study?

The aim of this study is to investigate service use and needs during the transitional years from adolescence to young adulthood and associated outcomes among those who have been diagnosed with ADHD. This will involve questionnaire based interviews at yearly intervals over a three year period.

- ADHD has largely been regarded as childhood developmental disorder despite growing evidence that symptoms continue into adulthood. Thus, few studies into the service use and needs of adolescents and young adults with these disorders have been conducted. Moreover, despite the transition to adult services being an important element of high quality service provision for an increasing number of young people with ADHD there has been little investigation of this issue.

Why have you been chosen?

We are inviting people (and their families) who were part of the IMAGE (International Multi-Centre ADHD Gene) project to take part in this study. We will be examining patterns of service use and needs and will look at how these change during the transitional years from adolescence to young adulthood. We are also interested in investigating the impact on these changes on your, and with your consent, your parent or partner's (if appropriate) well-being.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are still free to stop your participation and to have any research data withdrawn without giving any reason. Please

note that once analysis of the anonymised data is under way it will not be possible to have data withdrawn.

What will I have to do if I take part?

At a time convenient for you and (with your consent) your parent or partner (if appropriate) we will arrange to interview you both at home (or at the Institute of Psychiatry if you prefer, your travel expenses will be reimbursed). The interviews will take approximately one hour each (including a brief joint interview at the end). It is important for us to ask someone who knows you well, such as one of your parents (or your partner), to complete some of the same questions about you and to answer some questions about themselves. This is because it is sometimes difficult for young people to judge their own levels of attention and activity (as well as levels of service use and need)

To ensure confidentiality we will ask to carry out two separate interviews (preferably in two different rooms) with you and your parent/partner. It would be useful to carry out these interviews at the same time in order to save time and then to do a joint interview with both you and your parent/partner to ask a few more questions at the end. The interview with you will consist of answering some questions about your daily life (such as employment, study etc) and about your level of need (from your perspective). We will also ask questions about any other psychological symptoms you may have. In addition, we will ask you to complete a self-completion questionnaire. This self-completion questionnaire consists of three parts: (i) questions about your attention and activity levels over the last 6-months; (ii) a brief series of questions about your moods, and (iii) a series of questions on alcohol and drug use and any police contact.

The interview with your parent/partner will consist of answering the same questions about your behaviour in the past 6-months and your level of needs as best as they can (from their perspective). In addition, we will ask your parent/partner some questions about their daily life, current employment situation, and health. Following these two interviews we would also like to ask you and your parent or partner about the services you have used in the past few months and about your experiences of transitioning from child to adult services.

As a thank you for your time, you will be given a £20 gift voucher at the first interview.

What are the possible benefits of taking part?

Taking part in research projects is often a rewarding and interesting experience. The information we get from the study will help to better inform service use during the transitional years from adolescence to young adulthood among those with ADHD.

What are the possible disadvantages and risks of taking part?

There are no foreseeable risks in taking part in the study. The main disadvantage to taking part in the study is that you and your parent (or partner if appropriate) will be donating around an hour or so each of time every year for three years to take part. It is possible that you may find answering some of the questions distressing. This is unlikely but if it were to occur the interview could be terminated at any time.

Confidentiality

All personal information is regarded as strictly confidential and will be held securely until the research is completed. Your participation is voluntary. If you change your mind, you are free to stop your participation and to have your data withdrawn without giving any reason. All data for analysis will be anonymised.

What if something goes wrong?

We don't envisage any major risk associated with taking part in this study. In the event of you suffering any adverse effects as a consequence of your participation in this study, you will be compensated through the King's College London 'No Fault' Compensation Scheme. This scheme includes payment of damages or compensations in respect of any claim made by research participants for bodily injury arising out of participation in any clinical trial.

Consent

If in the unlikely event that, after giving informed consent, you were to lose capacity once the study had begun, participation would be terminated immediately and any identifiable data would be either anonymised or disposed of.

What will happen to the results of the research study?

This research will be analysed by researchers at the Institute of Psychiatry, King's College London (KCL), and the London School of Economics (LSE). The results will be used to inform health service provision and the development of services for ADHD. A report of the study findings can be sent to you once the research has been completed.

Who is organising and funding the research?

The National Institute for Health Research (NIHR) funds this research. This is government funding aimed at improving clinical diagnosis, treatment and health provision in the United Kingdom.

Who has reviewed the study?

The study has been subject to review by expert referees for the National Institute for Health Research. The NHS Research Ethics Committee has granted ethical approval.

Future research at King's:

We would like to be able to contact you with details of further research projects concerning young people with ADHD at the Institute of Psychiatry in the future. However, you are under no obligation to agree to be contacted about future participation.

Contact for further information:

Please ask if there is anything you do not understand or if you would like more information. If you have any concerns about your illness or want to find out more, please contact us and we will send you some more information.

If you should have any further questions you may discuss this with your GP. If you have specific questions about ADHD you may contact:

Hanna Eklund, Brain Maturation, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF

Tel: 0207 848 5359 Mob: 07812 487 226

E-mail: Hanna.Eklund@kcl.ac.uk

Deirdre Howley, Brain Maturation, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF

Tel: 0207 848 5359

E-mail: Deirdre.Howley@kcl.ac.uk

James Findon, Brain Maturation, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF
Tel: 0207 848 5359
E-mail: James.Findon@kcl.ac.uk

Dr Karen Glaser, King's College London, The Strand, London, WC2R 2LS
Tel: 020 7848 2554
E-mail: Karen.Glaser@kcl.ac.uk

Professor Philip Asherson, MRC Social Genetic and Developmental Psychiatry, The Institute of Psychiatry, De Crespigny Park, Denmark Hill London SE5 8AF.
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Phone: 02078485359, 07812 487 226
Email: Deidre.Howley@kcl.ac.uk
Phone: 02078485359
Email: James.Findon@kcl.ac.uk
Phone: 02078485359*

Date

Update Form Parents
20.10.10 version 2.0

I/ We have read the information provided and would be happy for a researcher to phone and discuss

this study ☐

I/We have read the information provide and do not wish to be contacted about

this study ☐ *(Please send back this form in the freepost envelope provided*

Signature

Parents Print name:

Address: Please provide details so that we can identify who you are and update our records.

Telephone:

Mobile number:

Email address:

We are now also interested in any children that you have (whether or not they have been diagnosed with ADHD and regardless of whether they are a full or half sibling). Please provide details of all your children.

| Child's name | Gender | D.O.B | Diagnosis (if applicable) |
|--------------|--------|-------|----------------------------|
| | | | Medication (if applicable) |

| | | | |
|--|--|--|--|
| | | | |
| | | | |
| | | | |
| | | | |

Do they all live with you? If not, would you be willing to provide us with contact details? If So, please fill in below.

Name:
Address:
Telephone number:
Mobile number:
Email address:
Does he/she live with a partner?

Name:
Address:
Telephone number:
Mobile number:
Email address:
Does he/she live with a partner?

Name:
Address:
Telephone number:
Mobile number:
Email address:
Does he/she live with a partner?

Please return in freepost envelope provided.



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*Prof. Philip Asherson
Dr Karen Glaser
Mrs Hanna Eklund
Miss Dee Howley
Mr James Findon*

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Phone: 02078485359, 07812 487 226
Email: Deidre.Howley@kcl.ac.uk
Phone: 02078485359
Email: James.Findon@kcl.ac.uk
Phone: 02078485359*

Date

Update Form Respondent
20.10.10 version 2.0

I/ We have read the information provided and would be happy for a researcher to phone and discuss this study ☐

I/We have read the information provide and do not wish to be contacted about this study ☐ *(Please send back this form in the freepost envelope provided)*

Signature

Print name:

Address: Please provide details so that we can identify who you are and update our records.

Telephone:

Mobile number:

Email address:

Please return in freepost envelope provided.

Prof. Philip Asherson
Dr Karen Glaser
Mrs Hanna Eklund
Miss Deirdre Howley
Mr James Findon

*Email: Hanna.Eklund@kcl.ac.uk
Tel: 02078485359 07812487226*
*Deirdre.Howley@kcl.ac.uk
Tel: 0207 848 5359*
*Email: James.Findon@kcl.ac.uk
Tel: 0207 848 5359*

To participate in this research, please read and sign the form below

| | | |
|--|-----|----|
| 1. I have read the information sheet, and I have been given a copy. I was given the opportunity to contact a member of the research team to ask questions. | YES | NO |
| 2. I consent to you contacting my mother/father/partner for information on my current and past mental health. | YES | NO |
| 3. I consent that the information gathered about me can be stored at the Institute of Psychiatry indefinitely until the research is completed. Any future work, and any extension of the project will be subject to review by a research ethics committee. | YES | NO |
| 4. I understand that I am free to stop my participation in this study at any time and that I can ask to have my data withdrawn without giving any reason. | YES | NO |
| 5. I consent to the input of anonymous data obtained from the information gathered about me into a computer, to be used for statistical analysis and research. | YES | NO |
| 6. I consent to be contacted about future ADHD research | YES | NO |
| 7. I would like to be sent information on the outcome of the study. | YES | NO |

I have explained the study and answered any questions from the participant honestly and fully

Contact details for research team: Hanna Eklund and Deirdre Howley, The Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF. Tel: 0207 848 5359, Mob: 07812 487 226
E-mail: Hanna.Eklund@kcl.ac.uk, Deirdre.Howley@kcl.ac.uk



Institute of Psychiatry
Social, Genetic and Developmental
Psychiatry Centre and Department of Child
and Adolescent Psychiatry

*Prof. Philip Asherson
Dr Karen Glaser
Mrs Hanna Eklund
Miss Dee Howley
Mr James Findon*

*Email: Hanna.Eklund@kcl.ac.uk
Tel: 02078483339, 07812487226
Deirdre.Howley@kcl.ac.uk
Tel: 0207 848 5359
Email: James.Findon@kcl.ac.uk
Tel: 0207 848 5359*

**Partner consent form
20.10.10 version 3.0**

To participate in this research, please read and sign the form below

Title of project: Study service use and needs among adolescents/young adults with ADHD

- | | | |
|---|------------------------------|-----------------------------|
| 1. I have read the information sheet, and I have been given a copy. I was given the opportunity to contact a member of the research team to ask questions. | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 2. I consent that the information I provide about myself and my partner can be stored at the Institute of Psychiatry indefinitely until the research is completed. Any future work and any extension of the project will be subject to review by a research ethics committee. | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 3. I understand that I am free to stop my participation in this study at any time and that I can ask to have my data withdrawn without giving any reason. | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 4. I consent to the input of anonymous data obtained from the information gathered about me into a computer, to be used for statistical analysis and research. | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 5. I consent to be contacted about future ADHD research | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 6. I would like to be sent information on the outcome of the study. | <input type="checkbox"/> YES | <input type="checkbox"/> NO |

| | | |
|--------------------------|---------------|--------------------|
| Name of partner | Date | Signature |
|--------------------------|---------------|--------------------|

I have explained the study and answered any questions from the participant honestly and fully

| | | |
|-----------------------------|---------------|--------------------|
| Name of researcher | Date | Signature |
|-----------------------------|---------------|--------------------|

Contact details for research team: Hanna Eklund and Deirdre Howley, The Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF. Tel: 0207 848 5359, Mob: 07812 487 226
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Appendix D Participant's interview booklet

| | | | | | | | | | | |
|----|--|--|---|--|--|---|--|--|--|--|
| ID | | | - | | | - | | | | |
|----|--|--|---|--|--|---|--|--|--|--|



PARTICIPANT'S INTERVIEW BOOKLET

Please indicate which interview this is

Baseline ☐ 12 months ☐ 24 months ☐

Participant name: _____

Participant date of birth: _____

Participant gender: _____

Date of interview: _____

Name of interviewer: _____

In this interview we are looking at the service use and needs of young people with ADHD and the impact of having this disorder. We know these factors are important and we would like to know how they affect you.

A. First, please tell us something about your daily life...

1. Do you still go to school or college?

INCLUDE TRAINING

Yes, full time ☐ (Go to (a))

Yes, part-time ☐ (Go to (a))

No, not in education ☐ (Go to Q2)

(a) What type of school or college did you attend last term?

SHOW CARD

| | <u>School</u> | <u>College</u> |
|------------------------|--------------------------|--------------------------|
| Mainstream day | <input type="checkbox"/> | <input type="checkbox"/> |
| Special residential | <input type="checkbox"/> | <input type="checkbox"/> |
| Special unit in m/s | <input type="checkbox"/> | <input type="checkbox"/> |
| Special day | <input type="checkbox"/> | <input type="checkbox"/> |
| University | | <input type="checkbox"/> |
| Other (describe) _____ | | <input type="checkbox"/> |

(b) Last term, did you miss any days from school/college?

Yes ☐

No ☐

If YES, how many days due to ADHD?

☐ ☐

If YES, how many days due to other reasons?

☐ ☐

(c) Last term, were there any days when your ADHD meant that you felt you couldn't do your school/ college work as well as you usually do?

Yes ☐

No ☐

If YES, how many days in the last term?

(d) In the last full term, did you have any extra help with education? By this I mean...

| | YES | If YES, how many times? | NO |
|---------------------------------|--------------------------|-------------------------|--------------------------|
| Individual tuition at home | <input type="checkbox"/> | | <input type="checkbox"/> |
| Individual help in some classes | <input type="checkbox"/> | | <input type="checkbox"/> |
| Some lessons in small classes | <input type="checkbox"/> | | <input type="checkbox"/> |

(e) In the last full term, did you see any of the following people in school/ college?

| | YES | If YES, how many times? | NO |
|--|--------------------------|-------------------------|--------------------------|
| School nurse | <input type="checkbox"/> | | <input type="checkbox"/> |
| Educational psychologist | <input type="checkbox"/> | | <input type="checkbox"/> |
| Educational welfare officer | <input type="checkbox"/> | | <input type="checkbox"/> |
| Special educational needs co-ordinator | <input type="checkbox"/> | | <input type="checkbox"/> |
| Additional meetings with teacher/tutor | <input type="checkbox"/> | | <input type="checkbox"/> |

2. Do you have a job?

Yes ☐ (Go to (a))

No ☐ (Go to Q3)

(a) What type of job is this (can include a saturday job)? _____

(b) How many hours do you usually work each week?

(c) Have you missed work in the last three months (SINCE DAY/MONTH)?

Yes ☐

No ☐

If YES, (SINCE DAY/MONTH) how many days due to ADHD?

If YES, (SINCE DAY/MONTH) how many days due to other

reasons?

(d) Have there been any days in the last 3 months (SINCE DAY/MONTH) when your ADHD meant that you felt you couldn't work as well as you usually do?

Yes ☐

No ☐

If YES, How many days?

3. IF NOT WORKING OR IN EDUCATION, Are you?
(SHOW CARD)

Unemployed ☐

Long-term sick ☐

Volunteer worker ☐

A housewife/husband ☐

Other (describe) _____ ☐

(a) In the last 3 months (SINCE DAY/MONTH), have there been any days when your ADHD meant that you felt you couldn't take part in your usual activities?

Yes ☐

No ☐

If YES, How many days?

(b) In the last 3 months (SINCE DAY/MONTH), have there been any days when your ADHD meant you couldn't do things as well as you usually do?

Yes ☐

No ☐

If YES, How many days?

GO TO CIS-R and CANDID

D. Now, lastly, please can I check a few things with you...

1. What would you say is your ethnic group?

- | | | | | | |
|--------------|--------------------------|--------------------|--------------------------|-------------------------|--------------------------|
| White- UK | <input type="checkbox"/> | Asian- Middle East | <input type="checkbox"/> | Asian – Oriental | <input type="checkbox"/> |
| Asian- Other | <input type="checkbox"/> | Black- Caribbean | <input type="checkbox"/> | Black- African | <input type="checkbox"/> |
| Black- Other | <input type="checkbox"/> | White- Irish | <input type="checkbox"/> | I do not wish to answer | <input type="checkbox"/> |
| White- Other | <input type="checkbox"/> | Other | <input type="checkbox"/> | | |

2. What is your current marital status?

- | | | | | | |
|---------------|--------------------------|---------|--------------------------|-----------------------|--------------------------|
| Never married | <input type="checkbox"/> | Married | <input type="checkbox"/> | Separated or divorced | <input type="checkbox"/> |
| Cohabiting | <input type="checkbox"/> | Widowed | <input type="checkbox"/> | | |

3. Have you ever...? Been married ☐ Cohabited ☐ Divorced ☐

4. IF NOT CURRENTLY A STUDENT, What is the highest educational qualification you have achieved? SHOW CARD

- | | |
|--|---|
| <input type="checkbox"/> Youth training certificate | <input type="checkbox"/> Certificate of Education (<i>Entry level, no GCSE's</i>) |
| <input type="checkbox"/> GCSE's (<i>grades D-G</i>) | <input type="checkbox"/> GCSE's (<i>grades A-C</i>) <input type="checkbox"/> A-levels |
| <input type="checkbox"/> Certificate of higher education | |
| <input type="checkbox"/> Diplomas of higher education/Foundations Degree/Higher National Diploma | |
| <input type="checkbox"/> Bachelor Degree/Graduate Certificate or Diploma | |
| <input type="checkbox"/> Masters Degree/Postgraduate Certificate or Diploma | |
| <input type="checkbox"/> PhD/Doctorate | |

5. Did you have a statement of 'special'/educational needs Yes ☐ No ☐

6. Were you ever excluded from school permanently? Yes ☐ No ☐

(a) If yes, How many times ☐☐

7. Were you ever excluded from school for short periods? Yes ☐ No ☐

(a) If yes, Approximately how many times ☐☐

8. Were you ever excluded from school informally? Yes ☐ No ☐

(a) If yes, how many times ☐☐

9. Who do you usually live with?

| | | | |
|--------------------------------|--------------------------|--------------------|--------------------------|
| Both natural parents | <input type="checkbox"/> | Adoptive Parents | <input type="checkbox"/> |
| Natural Mother and her partner | <input type="checkbox"/> | Residential home | <input type="checkbox"/> |
| Natural Father and his partner | <input type="checkbox"/> | Partner | <input type="checkbox"/> |
| Relative or Family Friends | <input type="checkbox"/> | Partner & children | <input type="checkbox"/> |
| Formal foster care | <input type="checkbox"/> | Alone | <input type="checkbox"/> |

10. In total, how many people live in the house? ☐☐

Over 16 years? ☐☐

Under 16 years? ☐☐

Appendix E Young person's self-completion booklet



PARTICIPANT'S SELF-COMPLETION **BOOKLET**

Your name: _____

Your date of birth: _____

Your gender: _____

Date: _____

A. CURRENT BEHAVIOUR SCALE – SELF-REPORT

Here we will ask you about behaviours you may have experienced during the past six months.

1. Please circle the number next to each item that best describes your behaviour

| Items: | Never or Rarely | Sometimes | Often | Very Often |
|---|--------------------|-----------|-------|---------------|
| Fail to give close attention to details or make careless mistakes in my work | 0 | 1 | 2 | 3 |
| Fidget with hands or feet or squirm in seat | 0 | 1 | 2 | 3 |
| Have difficulty sustaining my attention in tasks or fun activities | 0 | 1 | 2 | 3 |
| Leave my seat in situations in which sitting is expected | 0 | 1 | 2 | 3 |
| Don't listen when spoken to directly | 0 | 1 | 2 | 3 |
| Feel restless | 0 | 1 | 2 | 3 |
| Don't follow through on instructions and fail to finish work | 0 | 1 | 2 | 3 |
| Have difficulty engaging in leisure activities or doing fun things quietly | 0 | 1 | 2 | 3 |
| Have difficulty organising tasks and activities | 0 | 1 | 2 | 3 |
| Feel "on the go" or "driven by a motor" | 0 | 1 | 2 | 3 |
| Avoid, dislike, or am reluctant to engage in work that requires sustained mental effort | 0 | 1 | 2 | 3 |
| Talk excessively | 0 | 1 | 2 | 3 |
| Lose things necessary for tasks or activities | 0 | 1 | 2 | 3 |
| Blurt out answers before questions have been completed | 0 | 1 | 2 | 3 |
| Easily distracted | 0 | 1 | 2 | 3 |

| Items: | Never or Rarely | Sometimes | Often | Very Often |
|--------------------------------|--------------------|-----------|-------|---------------|
| Have difficulty awaiting turn | 0 | 1 | 2 | 3 |
| Forgetful in daily activities | 0 | 1 | 2 | 3 |
| Interrupt or intrude on others | 0 | 1 | 2 | 3 |

2. To what extent do the problems you may have circled above interfere with your ability to function in each of these areas of life activities? (please circle)

3.

| Areas: | Never or Rarely | Sometimes | Often | Very Often |
|---|--------------------|-----------|-------|---------------|
| In your home life with your immediate family | 0 | 1 | 2 | 3 |
| In your work or occupation | 0 | 1 | 2 | 3 |
| In your social interactions with others | 0 | 1 | 2 | 3 |
| In your activities or dealings in the community | 0 | 1 | 2 | 3 |
| In any educational activities | 0 | 1 | 2 | 3 |
| In your dating or marital relationship | 0 | 1 | 2 | 3 |
| In your management of money | 0 | 1 | 2 | 3 |
| In your driving of a motor vehicle | 0 | 1 | 2 | 3 |
| In your leisure or recreational activities | 0 | 1 | 2 | 3 |
| In your management of your daily responsibilities | 0 | 1 | 2 | 3 |

B. MOOD QUESTIONNAIRE

In this part we will ask you about your moods.

3. Using the scale below, circle the number that best describes how often each item has appeared in your behavior in the past 5 years, and how often it has appeared in the last month.

| Applies Never | Rarely | Occasionally | Frequently | Most of the time |
|---------------|--------|--------------|------------|------------------|
| 0 | 1 | 2 | 3 | 4 |

***For each item, circle only one answer.**

People have told me at times that I seem to get upset very easily or that I get upset over little things.

| | | | | | |
|--------------|---|---|---|---|---|
| Past 5 years | 0 | 1 | 2 | 3 | 4 |
| Last month | 0 | 1 | 2 | 3 | 4 |

I've noticed that I get upset very easily.

| | | | | | |
|--------------|---|---|---|---|---|
| Past 5 years | 0 | 1 | 2 | 3 | 4 |
| Last month | 0 | 1 | 2 | 3 | 4 |

Others have told me that I seem to get frustrated very easily or that I seem to get frustrated over little things.

| | | | | | |
|--------------|---|---|---|---|---|
| Past 5 years | 0 | 1 | 2 | 3 | 4 |
| Last month | 0 | 1 | 2 | 3 | 4 |

I can quickly go from feeling calm to feeling very angry over little things or for no reason at all.

| | | | | | |
|--------------|---|---|---|---|---|
| Past 5 years | 0 | 1 | 2 | 3 | 4 |
| Last month | 0 | 1 | 2 | 3 | 4 |

At times I can be feeling no more impatient than others but then I'll suddenly become very impatient over something small or for no reason at all.

| | | | | | |
|--------------|---|---|---|---|---|
| Past 5 years | 0 | 1 | 2 | 3 | 4 |
| Last month | 0 | 1 | 2 | 3 | 4 |

First interview

People have told me at times that I seem to get impatient very easily or that I seem to get impatient over little things.

| | | | | | |
|--------------|---|---|---|---|---|
| Past 5 years | 0 | 1 | 2 | 3 | 4 |
| Last month | 0 | 1 | 2 | 3 | 4 |

Others have told me that I seem to get nervous very easily or that I seem to become nervous over little things.

| | | | | | |
|--------------|---|---|---|---|---|
| Past 5 years | 0 | 1 | 2 | 3 | 4 |
| Last month | 0 | 1 | 2 | 3 | 4 |

Sometimes I can be feeling fine one minute and then I'll yell or raise my voice in an angry way the next.

| | | | | | |
|--------------|---|---|---|---|---|
| Past 5 years | 0 | 1 | 2 | 3 | 4 |
| Last month | 0 | 1 | 2 | 3 | 4 |

a) If you had one of these symptoms, at what age did you first notice this behavior?

C. DRUG USE-SELF-REPORT

In this section we will ask you about drug use (such as cannabis, speed and heroin).

For each of the items below, please tick YES or NO.

4. Have you ever used Cannabis, even if just once? Yes ☐ No ☐

(a) If yes, how old were you when you first used it? _____

(b) If yes, have you used Cannabis in the last month? Yes ☐ No ☐

5. Have you ever used any other drug? (If no, please go to section D)

6. Have you ever used inhalants (liquids, sprays, glue)? Yes ☐ No ☐

(a) If yes, how old were you when you first used it? _____

(b) If yes, have you used inhalants in the last month? Yes ☐ No ☐

7. Have you ever used ECSTASY? Yes ☐ No ☐

(a) If yes, how old were you when you first used it? _____

(b) If yes, have you used ECSTASY in the last month? Yes ☐ No ☐

8. Have you ever used amphetamines (speed)? Yes ☐ No ☐

(a) If yes, how old were you when you first used it? _____

(b) If yes, have you used amphetamines (speed) in the last month?

Yes ☐ No ☐

9. Have you ever used LSD (Acid)? Yes ☐ No ☐

(a) If yes, how old were you when you first used it? _____

(b) If yes, have you used LSD in the last month? Yes ☐ No ☐

10. Have you ever used Tranquillisers (Valium, Temezapan) Yes ☐ No ☐

(a) If yes, how old were you when you first used it? _____

(b) If yes, have you used Tranquillisers (Valium, Temezapan) in the last month?

Yes ☐ No ☐

11. Have you ever used Cocaine (Crack)?

Yes ☐ No ☐

(a) If yes, how old were you when you first used it? _____

(b) If yes, have you used Cocaine in the last month?

Yes ☐ No ☐

12. Have you ever used Heroin (Methadone) ?

Yes ☐ No ☐

(a) If yes, how old were you when you first used it? _____

(b) If yes, have you used Heroine (Methadone) in the last month? Yes ☐ No ☐

13. Have you ever had any help or treatment because you were using drugs?

Yes ☐ No ☐

14. Have you ever got into trouble for using drugs (e.g. at school, at home, with police)?

Yes ☐ No ☐

D. ALCOHOL USE-SELF-REPORT

The next few questions are about alcohol use. Please tick the box that best applies to you.

15. How often do you have a drink containing alcohol?

- ☐ Never *(if never, please ignore this section and go to page 9)*
- ☐ Weekly
- ☐ Monthly
- ☐ Two or four times a month
- ☐ Two or three times a week
- ☐ Four or more times a week

16. How many drinks containing alcohol do you have in a typical day when you are drinking?

- ☐ 1 or 2
- ☐ 3 or 4
- ☐ 5 or 6
- ☐ 7 to 9
- ☐ 10 or more

17. How often do you have six or more drinks on any one occasion?

- ☐ Never
- ☐ Less than monthly
- ☐ Monthly
- ☐ Weekly
- ☐ Daily or almost daily

18. How often during the last year have you found that you were not able to stop drinking once you had started?

- ☐ Never
- ☐ Less than monthly
- ☐ Monthly
- ☐ Weekly

☐ Daily or almost daily

19. How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?

☐ Never

☐ Less than monthly

☐ Monthly

☐ Weekly

☐ Daily or almost daily

20. How often during the last year have you had a feeling of guilt or remorse after drinking?

☐ Never

☐ Less than monthly

☐ Monthly

☐ Weekly

☐ Daily or almost daily

21. How often during the last year have you been unable to remember what happened the night before because you had been drinking?

☐ Never

☐ Less than monthly

☐ Monthly

☐ Weekly

☐ Daily or almost daily

22. Have you or someone else been injured because of your drinking?

☐ No

☐ Yes, but not in the last year

☐ Yes, during the last year

23. Has a relative, friend, or doctor or other health worker been concerned about your drinking or suggested that you should cut down?

- ☐ No
- ☐ Yes, but not in the last year
- ☐ Yes, during the last year

E. ABOUT TROUBLE WITH POLICE

In question 24 please tick the box that applies to you and then answer the remaining questions if you answered yes to 24.

24. Have you been in trouble with the police in the last 12 months?

Yes ☐ No ☐

If yes,

How many formal police cautions have you had?

What were these cautions for?

How many times have you appeared in court?

How many community sentences have you had?

How many weeks of community sentence in total?

How many nights have you spent in a police cell?

How many nights have you spent in youth custody?

How many nights have you spent in prison?

Thank you for answering these questions!

Appendix F Parent/partner interview booklet



PARENT/PARTNER INTERVIEW BOOKLET

Please indicate which interview this is

Baseline ☐ 12 months ☐ 24 months ☐

Parent/Partner name: _____

Parent/Partner of: _____

Nature of relationship: _____

Parent/Partner date of birth: _____

Parent/Partner gender: _____

Date of interview: _____

Name of interviewer: _____

A. CURRENT BEHAVIOUR SCALE – SELF-REPORT

Here we will ask you about your son/daughter/partner's behaviours during the past six months.

1. Please circle the number next to each item that best describes his/her behaviour

| Items: | Never or Rarely | Sometimes | Often | Very Often |
|---|--------------------|-----------|-------|------------|
| Fail to give close attention to details or make careless mistakes in my work | 0 | 1 | 2 | 3 |
| Fidget with hands or feet or squirm in seat | 0 | 1 | 2 | 3 |
| Have difficulty sustaining my attention in tasks or fun activities | 0 | 1 | 2 | 3 |
| Leave my seat in situations in which sitting is expected | 0 | 1 | 2 | 3 |
| Don't listen when spoken to directly | 0 | 1 | 2 | 3 |
| Feel restless | 0 | 1 | 2 | 3 |
| Don't follow through on instructions and fail to finish work | 0 | 1 | 2 | 3 |
| Have difficulty engaging in leisure activities or doing fun things quietly | 0 | 1 | 2 | 3 |
| Have difficulty organising tasks and activities | 0 | 1 | 2 | 3 |
| Feel "on the go" or "driven by a motor" | 0 | 1 | 2 | 3 |
| Avoid, dislike, or am reluctant to engage in work that requires sustained mental effort | 0 | 1 | 2 | 3 |
| Talk excessively | 0 | 1 | 2 | 3 |
| Lose things necessary for tasks or activities | 0 | 1 | 2 | 3 |
| Blurt out answers before questions have been completed | 0 | 1 | 2 | 3 |
| Easily distracted | 0 | 1 | 2 | 3 |

| Items: | Never or Rarely | Sometimes | Often | Very often |
|--------------------------------|--------------------|-----------|-------|------------|
| Have difficulty awaiting turn | 0 | 1 | 2 | 3 |
| Forgetful in daily activities | 0 | 1 | 2 | 3 |
| Interrupt or intrude on others | 0 | 1 | 2 | 3 |

2. To what extent do the problems you may have circled on the previous page interfere with his/her ability to function in each of these areas of life activities?

| Areas: | Never or Rarely | Sometimes | Often | Very Often |
|--|--------------------|-----------|-------|------------|
| In his/her home life with his/her immediate family | 0 | 1 | 2 | 3 |
| In his/her work or occupation | 0 | 1 | 2 | 3 |
| In his/her social interactions with others | 0 | 1 | 2 | 3 |
| In his/her activities or dealings in the community | 0 | 1 | 2 | 3 |
| In any educational activities | 0 | 1 | 2 | 3 |
| In his/her dating or marital relationship | 0 | 1 | 2 | 3 |
| In his/her management of money | 0 | 1 | 2 | 3 |
| In his/her driving of a motor vehicle | 0 | 1 | 2 | 3 |
| In his/her leisure or recreational activities | 0 | 1 | 2 | 3 |
| In his/her management of daily responsibilities | 0 | 1 | 2 | 3 |

| |
|-------------------------------|
| B. RECEIPT OF SERVICES |
|-------------------------------|

3. Do you think that your son/daughter/partner's ADHD has affected your health?

Yes ☐ (Go to Q4)

No ☐ (Go to Q7)

4. Please tell us a little about the services you have seen. Did you seek help from any formal services?

Yes ☐ (Go to Q5)

No ☐ (Go to Q6)

5. Which of the following services have you used in the last 3 months (SINCE DAY/MONTH)?

| | YES | If YES, how many times? | NO |
|-------------------------------------|--------------------------|-------------------------|--------------------------|
| GP | <input type="checkbox"/> | | <input type="checkbox"/> |
| Practice Nurse | <input type="checkbox"/> | | <input type="checkbox"/> |
| Hospital Outpatient Clinic | <input type="checkbox"/> | | <input type="checkbox"/> |
| Counsellor | <input type="checkbox"/> | | <input type="checkbox"/> |
| Alternative therapist (shiatsu etc) | <input type="checkbox"/> | | <input type="checkbox"/> |
| Self-help or support group | <input type="checkbox"/> | | <input type="checkbox"/> |
| Telephone help-line | <input type="checkbox"/> | | <input type="checkbox"/> |

6. Have you seen any other services because of your son/daughter/partner's ADHD?

IF YES, What were these services?

- ☐ Psychologist ☐ Social services ☐ Church community
- ☐ Online website ☐ Other (please describe) _____

GO TO SECTION C (CANDID).

D. Please tell us something about your daily life...

7. What is the highest educational qualification you have achieved?
(SHOW CARD)

- ☐ Youth training certificate ☐ Certificate of Education (*Entry level, no GCSE's*)
- ☐ GCSE's (*grades D-G*) ☐ GCSE's (*grades A-C*) ☐ A-levels
- ☐ Certificate of higher education
- ☐ Diplomas of higher education/Foundations Degree/Higher National Diploma
- ☐ Bachelor Degree/Graduate Certificate or Diploma
- ☐ Masters Degree/Postgraduate Certificate or Diploma
- ☐ PhD/Doctorate

8. Which of the following best describes your work situation? (PROMPT 'what you spend most time doing') (SHOW CARD)

- | | | |
|---|---|----------------------------------|
| <input type="checkbox"/> Paid employment | <input type="checkbox"/> Volunteer work | |
| <input type="checkbox"/> Primary housemaker | <input type="checkbox"/> Long-term sick | |
| <input type="checkbox"/> Unemployed | <input type="checkbox"/> Student | <input type="checkbox"/> Retired |

IF NOT IN EMPLOYMENT GO TO Q13

9. What is your job/occupation? _____

10. How many hours a week do you usually work in this job?

11. In the last 3 months (SINCE DAY/MONTH), have you had any days 'off sick' because of your carer role?

Yes ☐ No ☐

(a) If yes, How many days?

12. In the last 3 months (SINCE DAY/MONTH), have there been any days when your carer role meant that you felt you couldn't do as well as you usually do?

Yes ☐ No ☐

(b) If yes, How many days?

IF NOT IN PAID EMPLOYMENT OR VOLUNTEER WORK PLEASE ASK THESE QUESTIONS

13. In the last 3 months (SINCE DAY/MONTH), have there been any days when your carer role meant that you felt you couldn't take part in your usual activities?

Yes ☐ No ☐

(a) If yes, How many days? ☐☐

14. In the last 3 months (SINCE DAY/MONTH), have there been any days when your carer role meant you couldn't do things as well as you usually do?

Yes ☐ No ☐

(b) If yes, How many days? ☐☐

| |
|---------------------------------|
| E. SF-12 (Health Survey) |
|---------------------------------|

15. How is your health in general?

Would you say your health is....

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

16. Does your health now limit you in moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?

Yes ☐ No ☐

(ASK IF YES)

(a) And how much does your health now limit you with these activities?

- ☐ A little
- ☐ A lot

17. Does your health now limit you in climbing several flights of stairs?

Yes ☐ No ☐

(ASK IF YES)

(a) And how much does your health now limit you with this activity?

- ☐ A little
- ☐ A lot

18. During the past 4 weeks [SINCE DAY/MONTH], have you accomplished less than you would like to with your work or other regular daily activities as a result of your physical health?

Yes ☐ No ☐

19. During the past 4 weeks [SINCE DAY/MONTH], were you limited in the kind of work or other activities you could do as a result of your physical health?

Yes ☐ No ☐

20. During the past 4 weeks [SINCE DAY/MONTH], have you accomplished less than you would like to with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

Yes ☐ No ☐

21. And during the past 4 weeks [SINCE DAY/MONTH], did you not do work or other activities as carefully as usual as a result of your emotional health?

Yes ☐ No ☐

22. During the past 4 weeks [SINCE DAY/MONTH], how much did pain interfere with your normal work (including both work outside the home and housework)?
(SHOW CARD)

- ☐ Not at all
- ☐ A little bit
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

These questions are about how you feel and how things have been with you in the past 4 weeks) For each question, please look at this card and give the one answer that comes closest to the way you have been feeling.

23. How much of the time during the past 4 weeks [SINCE DAY/MONTH], have you felt calm and peaceful? (SHOW CARD)

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

24. And how much of the time during the past 4 weeks [SINCE DAY/MONTH], did you have a lot of energy? (SHOW CARD)

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

25. And how much of the time during the past 4 weeks [SINCE DAY/MONTH], have you felt downhearted and low? (SHOW CARD)

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

26. During the past 4 weeks SINCE DAY/MONTH], how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends or relatives etc.)?
(SHOW CARD)

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

F. Zarit Carer Burden Interview

Next few questions are about caring for your son/daughter/partner and how this may sometimes make you feel. I am going to read a few statements and ask you to tell me how often you may feel in certain ways.

27. Do you feel that because of the time you spend with your relative you don't get enough time for yourself? How often would you say you feel like this?
(SHOW CARD)

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Never | <input type="checkbox"/> Quite Frequently |
| <input type="checkbox"/> Rarely | <input type="checkbox"/> Nearly always |
| <input type="checkbox"/> Sometimes | |

28. Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)? How often would you say you feel like this?
(SHOW CARD)

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Never | <input type="checkbox"/> Quite Frequently |
| <input type="checkbox"/> Rarely | <input type="checkbox"/> Nearly always |
| <input type="checkbox"/> Sometimes | |

29. Do you feel angry when you are around your relative? How often would you say you feel like this?
(SHOW CARD)

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Never | <input type="checkbox"/> Quite Frequently |
| <input type="checkbox"/> Rarely | <input type="checkbox"/> Nearly always |
| <input type="checkbox"/> Sometimes | |

30. Do you feel that your relative currently affects your relationship with family members or friends in a negative way? How often would you say you feel like this? (SHOW CARD)

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Never | <input type="checkbox"/> Quite Frequently |
| <input type="checkbox"/> Rarely | <input type="checkbox"/> Nearly always |
| <input type="checkbox"/> Sometimes | |

31. Do you feel strained when you are around your relative? How often would you say you feel like this? (SHOW CARD)

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Never | <input type="checkbox"/> Quite Frequently |
| <input type="checkbox"/> Rarely | <input type="checkbox"/> Nearly always |
| <input type="checkbox"/> Sometimes | |

32. Do you feel that your health has suffered because of your involvement with your relative? How often would you say you feel like this? (SHOW CARD)

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Never | <input type="checkbox"/> Quite Frequently |
| <input type="checkbox"/> Rarely | <input type="checkbox"/> Nearly always |
| <input type="checkbox"/> Sometimes | |

33. Do you feel that you don't have as much privacy as you would like to because of your relative? How often would you say you feel like this? (SHOW CARD)

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Never | <input type="checkbox"/> Quite Frequently |
| <input type="checkbox"/> Rarely | <input type="checkbox"/> Nearly always |
| <input type="checkbox"/> Sometimes | |

34. Do you feel that your social life has suffered because you are caring for your relative? How often would you say you feel like this? (SHOW CARD)

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Never | <input type="checkbox"/> Quite Frequently |
| <input type="checkbox"/> Rarely | <input type="checkbox"/> Nearly always |
| <input type="checkbox"/> Sometimes | |

35. Do you feel that you have lost control of your life since your relative's illness? How often would you say you feel like this? (SHOW CARD)

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Never | <input type="checkbox"/> Quite Frequently |
| <input type="checkbox"/> Rarely | <input type="checkbox"/> Nearly always |
| <input type="checkbox"/> Sometimes | |

36. Do you feel uncertain about what to do about your relative? How often would you say you feel like this? (SHOW CARD)

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Never | <input type="checkbox"/> Quite Frequently |
| <input type="checkbox"/> Rarely | <input type="checkbox"/> Nearly always |
| <input type="checkbox"/> Sometimes | |

37. Do you feel you should be doing more for your relative? How often would you say you feel like this? (SHOW CARD)

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Never | <input type="checkbox"/> Quite Frequently |
| <input type="checkbox"/> Rarely | <input type="checkbox"/> Nearly always |
| <input type="checkbox"/> Sometimes | |

38. Do you feel you could do a better job in caring for your relative? How often would you say you feel like this? (SHOW CARD)

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Never | <input type="checkbox"/> Quite Frequently |
| <input type="checkbox"/> Rarely | <input type="checkbox"/> Nearly always |
| <input type="checkbox"/> Sometimes | |

G. DEMOGRAPHICS

Now, lastly, please can I check a few things with you...

39. What would you say is your ethnic group?

- | | | | | | |
|--------------|--------------------------|--------------------|--------------------------|-------------------------|--------------------------|
| White- UK | <input type="checkbox"/> | Asian- Middle East | <input type="checkbox"/> | Asian – Oriental | <input type="checkbox"/> |
| Asian- Other | <input type="checkbox"/> | Black- Caribbean | <input type="checkbox"/> | Black- African | <input type="checkbox"/> |
| Black- Other | <input type="checkbox"/> | White- Irish | <input type="checkbox"/> | I do not wish to answer | <input type="checkbox"/> |
| White- Other | <input type="checkbox"/> | Other | <input type="checkbox"/> | | |

40. What is your current marital status?

- | | | | | | |
|------------|--------------------------|-----------------------|--------------------------|---------------|--------------------------|
| Married | <input type="checkbox"/> | Separated or divorced | <input type="checkbox"/> | Never married | <input type="checkbox"/> |
| Cohabiting | <input type="checkbox"/> | Widowed | <input type="checkbox"/> | | |

41. Have you ever....? Been married ☐ Cohabited ☐ Divorced ☐

42. Please tell me about the type of house you live in. Is it:

- | | | | | | |
|----------------|--------------------------|----------------|--------------------------|---------------------|--------------------------|
| Owner Occupied | <input type="checkbox"/> | Council Rented | <input type="checkbox"/> | Housing Association | <input type="checkbox"/> |
| Private Rented | <input type="checkbox"/> | | | | |

43. Are you a carer for anyone else? Yes ☐ No ☐

Appendix G Joint interview booklet

| | | | | | | | | | | |
|----|--|--|---|--|--|---|--|--|--|--|
| ID | | | - | | | - | | | | |
|----|--|--|---|--|--|---|--|--|--|--|



JOINT INTERVIEW BOOKLET

Please indicate which interview this is

Baseline ☐ 12 months ☐ 24 months ☐

Name of participant: _____

Date of birth of participant: _____

Gender: _____

Name of parent/partner: _____

Relationship: _____

Date of interview: _____

Name of interviewer: _____

SERVICE RECEIPT INVENTORY

Section A: Information on service use in last 3 months

1. Have you stayed in hospital for ADHD or any mental health problem in the last 3 months (SINCE DAY/MONTH)?

☐ Yes ☐ No

If YES,

| Admission | Reason for stay | No of inpatient days in the last 3 months |
|-----------|-----------------|---|
| 1 | | |
| 2 | | |
| 3 | | |

2. Have you stayed in hospital for other reasons, other than ADHD or any mental health problems, in the last 3 months (SINCE DAY/MONTH)?

☐ Yes ☐ No

If YES,

| Admission | Reason for stay | No of inpatient days in the last 3 months |
|-----------|-----------------|---|
| 1 | | |
| 2 | | |
| 3 | | |

3. Have you seen any of the following services in the last 3 months (SINCE DAY/MONTH)? If you're not sure, I'd rather you told me that you're not sure rather than guessed.

| Hospital services | YES | If YES, how many times? | NO | Not sure |
|-------------------------------------|--------------------------|-------------------------|--------------------------|--------------------------|
| Paediatric (ADHD) outpatient clinic | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> |
| Adult (ADHD) outpatient clinic | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> |
| Paediatric outpatient clinic | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> |
| Adult outpatient clinic | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> |
| A & E or Minor Injuries Unit | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> |

4. And what about the following services, have you seen... ?

| | YES | If YES, how many times? | NO |
|--|--------------------------|-------------------------|--------------------------|
| Have you seen the GP for ADHD in the last 3 months? | <input type="checkbox"/> | | <input type="checkbox"/> |
| Have you seen the GP for other reasons than for ADHD in the last 3 months? | <input type="checkbox"/> | | <input type="checkbox"/> |
| Have you seen the Practice Nurse for ADHD in the last 3 months? | <input type="checkbox"/> | | <input type="checkbox"/> |
| Have you seen the Practice Nurse for other reasons than for ADHD in the last 3 months? | <input type="checkbox"/> | | <input type="checkbox"/> |
| Have you had any repeat prescriptions in the last 3 months? | <input type="checkbox"/> | | <input type="checkbox"/> |

5. And have you seen any of the following professionals in the last months (SINCE DAY/MONTH)?

| Community Services | YES | If YES, how many times? | NO | Not sure |
|------------------------------------|--------------------------|-------------------------|--------------------------|--------------------------|
| Psychiatrist | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> |
| Psychiatric Nurse/Nurse Specialist | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> |
| Psychologist | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> |
| Family Therapist | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> |
| Social Worker | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> |
| OT (Occupational Therapist) | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> |

6. Do you know if any of these services (at question 5) were part of Child and Adolescent Community Services or Adult Community Services?

- ☐ Yes, CAMHS
 ☐ Yes, AMHS
☐ Yes, both
 ☐ Not sure/ don't know

7. And finally, have you seen any of the following professionals in the last 3 months?

| General Community Services | YES | If YES, how many times? | NO |
|--|--------------------------|-------------------------|--------------------------|
| Specialist Doctor (for physical problems) | <input type="checkbox"/> | | <input type="checkbox"/> |
| Counsellor | <input type="checkbox"/> | | <input type="checkbox"/> |
| Alternative Therapist (reiki etc): (insert) | <input type="checkbox"/> | | <input type="checkbox"/> |
| Key Worker | <input type="checkbox"/> | | <input type="checkbox"/> |
| Solicitor or Lawyer | <input type="checkbox"/> | | <input type="checkbox"/> |
| Self-help/support group | <input type="checkbox"/> | | <input type="checkbox"/> |
| Home help/home care worker | <input type="checkbox"/> | | <input type="checkbox"/> |
| Family Support Worker | <input type="checkbox"/> | | <input type="checkbox"/> |
| Websites/Helplines | <input type="checkbox"/> | | <input type="checkbox"/> |
| ADHD Coach | <input type="checkbox"/> | | <input type="checkbox"/> |

8. Have you used any services not listed here? (e.g. family centre)? Please tell us what these services were and how often you used them

9. What about things you pay for? (e.g. special nutritional supplements or over the counter medications)? How often/how much do you pay out of your own pocket?

Section B: TRANSITIONS IN CARE

Now I am going to ask you about moving from child to adult services (some people call this transitioning). We want to ask you what you thought about this and whether or not you received any help when you moved from child to adult services [if has transitioned]/ what help you would like [if hasn't transitioned].

10. Are you now being dealt with by children or adult services?

- ☐ Children's services
 ☐ Adult services (go to 12)
 ☐ Services with no age boundary
☐ Don't know
 ☐ Neither

11. [If hasn't left children's services] Has anyone started planning or talked to you about your move from child to adult services?

☐ Yes ☐ No (go to 17)

12. [If has transitioned or is currently receiving planning for transition] How old were you when services first started planning for your move from child to adult services?

☐☐

13. Do you/did you have a written transition plan?

☐ Yes ☐ No ☐ Don't know

14. Do you/did you have a copy of this transition plan?

☐ Yes ☐ No ☐ Don't know

15. How often is/was this planning reviewed? ☐☐

16. Do you feel that your transition plans are/were reviewed regularly enough?

☐ Yes ☐ No ☐ Not reviewed

17. [FOR CHILD] Concerning *information* on your move from child to adults services, how much help did you need/ do you need from services in the following areas?

| | Help not needed (yet) | Got/getting enough help | Need help/need more help |
|---|--------------------------|--------------------------|--------------------------|
| Information to help you plan for your future | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Someone to show you which services are available as you as you grows up | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Someone to explain the transition process to you | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

18. [FOR PARENT/PARTNER] Concerning *information* on your child/partner's transition, how much help did you feel that your child needed/does your child need or will need from services in the following areas.

| | Help not needed (yet) | Got/getting enough help | Needed help/need more help |
|--|--------------------------|--------------------------|----------------------------|
| Information for your child/partner about future options | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Someone for your child/partner to talk/communicate with about transition | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Someone to explain the transition process to your child/partner | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Section C: Co-ordinated approach to transition

19. Did you have ONE person to support you and your son/daughter through the move from child to adult services?

☐ Yes

☐ No (go to Q.25)

☐ Don't know (go to Q25)

20. What was this person's job title?

☐ Transition worker

☐ Teacher

☐ Social worker

☐ Nurse

☐ Key worker

☐ Connexions worker

☐ Lead professional

☐ Don't know

☐ Other (please state) _____

21. Approximately how long did you have this support?

_____ months _____ years

22. Would you have liked to have seen this person ...

☐ More often

☐ About the same

☐ Less often?

23. Would you have liked to have talked to this person ...

☐ More often

☐ About the same

☐ Less often?

24. Regarding contact with this person:

a) Did they contact you regularly?

☐ Yes

☐ No

☐ Don't know

b) Did they usually leave it up to you to contact them?

☐ Yes

☐ No

☐ Don't know

25. Concerning how your move from child to adult services is/was co-ordinated, how much help did you have or feel that you needed from services in the following areas.

| | Help not need(ed) yet | Got enough help | Need(ed) help/need(ed) more help |
|---|--------------------------|--------------------------|----------------------------------|
| Someone to talk to about your transition | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Someone speaking on behalf of the family when dealing with transition issues | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Someone looking at your needs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Someone looking at your needs (mother) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Someone providing individual support for you (e.g. emotional and practical support) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Someone co-ordinating your transition | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | | | |
|---|--------------------------|--------------------------|--------------------------|
| Someone helping you to find suitable services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|---|--------------------------|--------------------------|--------------------------|

26. Overall, how satisfied were you with the service you currently receiving/were you with the services you received?

☐ Very satisfied ☐ Satisfied ☐ Not satisfied ☐ Not at all satisfied

27. Overall, how well managed was the process of moving from child to adult services between:

| | Managed well | Managed OK | Poorly managed | Don't know | Not applicable |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Children's and adult <u>social</u> care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Children's and adult <u>health</u> services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Appendix H Participant socio-demographic and health characteristics

| Characteristic | Percentage values | Raw number values (n) | Missing (n) |
|---|-------------------|-----------------------|-------------|
| Mean age (yrs) (SD) | | 17.5 (2.3) | 0 |
| 14-17 year olds, % | 44 | 36 | |
| 18-21 year olds, % | 56 | 46 | |
| Gender (Male %) | 89 | 73 male: 9 female | 0 |
| Ethnicity | | | |
| White or White British, % | 100 | 82 | 0 |
| Living Arrangements | | | |
| Lives with both natural parents, % | 72 | 59 | 0 |
| Lives with natural mother (and her partner), % | 13 | 11 | 0 |
| Lives with natural father (and his partner), % | 2 | 2 | 0 |
| Lives with partner, % | 2 | 2 | 0 |
| Lives with relative or with friend, % | 1 | 1 | 0 |
| Lives with non-relative, % | 4 | 3 | 0 |
| Alone, % | 1 | 1 | 0 |
| Other, % | 4 | 3 | 0 |
| Marital Status | | | |
| Never married,% | 96 | 79 | 0 |
| Married/living with partner,% | 4 | 3 | 0 |
| Status | | | |
| Not in education, % | 34 | 28 | 0 |
| In education, % | 66 | 54 | 0 |
| Full-time education, % | 57 | 47 | 0 |
| Part-time education, % | 9 | 7 | 0 |
| Employed (incl. voluntary and part-time work), % | 37 | 30 | 0 |
| Unemployed and not in education, % | 16 | 13 | 0 |
| Statement of Special Educational Needs (SEN), % | 15 | 12 | 0 |
| Exclusions from school | | | |
| Any exclusion from school, % | 50 | 41 | 0 |
| Permanent exclusions, % | 10 | 12 | 0 |
| Exclusions for short periods, % | 38 | 31 | 0 |
| ADHD | | | |
| Below threshold (DSM-IV), % | 27 | 22 | 2 |
| Above threshold (DSM-IV), % | 73 | 58 | 2 |
| Combined Type ADHD, % | 31 | 25 | 2 |
| Predominantly Inattentive Type, % | 35 | 28 | 2 |
| Predominantly Hyperactive-Impulsive Type, % | 6 | 5 | 2 |
| Impairments in daily activities | | | |
| Significant impairment in at least one life activity, % | 90 | 71 | 3 |
| Hazardous drinking or drug use, % | 66 | 50 | 6 |
| Alcohol use | | | |
| No hazardous drinking, % | 35 | 27 | 6 |
| Hazardous drinking, % | 65 | 49 | 6 |
| Drug use | | | |
| Have used Cannabis in the past (even if just once), % | 47 | 36 | 5 |
| Have used Cannabis in the last month, % | 22 | 17 | 5 |
| Have used another drug in the past, % | 21 | 16 | 5 |
| Have used another drug in the last month, % | 12 | 9 | 5 |
| Problems with police | | | |
| Have been in trouble with the police in the last 12 months, % | 26 | 20 | 5 |
| Psychiatric comorbidity | | | |
| No significant neurotic symptoms, % | 73 | 59 | 1 |
| Significant neurotic symptoms, % | 27 | 22 | 1 |

Appendix I NICE (2008) recommendations for treatment for school-aged children and young people with moderate ADHD

1.5.2.1 Drug treatment is not indicated as the first-line treatment for all school-age children and young people with ADHD. It should be reserved for those with severe symptoms and impairment or for those with moderate levels of impairment who have refused non-drug interventions, or whose symptoms have not responded sufficiently to parent-training/education programmes or group psychological treatment.

1.5.2.3 Teachers who have received training about ADHD and its management should provide behavioural interventions in the classroom to help children and young people with ADHD.

1.5.2.4 If the child or young person with ADHD has moderate levels of impairment, the parents or carers should be offered referral to a group parent-training/education programme, either on its own or together with a group treatment programme (CBT and/or social skills training) for the child or young person.

1.5.2.5 When using group treatment (CBT and/or social skills training) for the child or young person in conjunction with a parent-training/education programme, particular emphasis should be given to targeting a range of areas, including social skills with peers, problem solving, self-control, listening skills and dealing with and expressing feelings. Active learning strategies should be used, and rewards given for achieving key elements of learning.

1.5.2.6 For older adolescents with ADHD and moderate impairment, individual psychological interventions (such as CBT or social skills training) may be considered as they may be more effective and acceptable than group parent-training/education programmes or group CBT and/or social skills training.

1.5.2.7 For children and young people (including older age groups) with ADHD and a learning disability, a parent-training/education programme should be offered on either a group or individual basis, whichever is preferred following discussion with the parents or carers and the child or young person.

1.5.2.8 When parents or carers of children or young people with ADHD undertake parent-training/education programmes, the professional delivering the sessions should consider contacting the school and providing the child or young person's teacher with written information on the areas of behavioural management covered in these sessions. This should only be done with parental consent.

1.5.2.9 Following successful treatment with a parent-training/education programme and before considering discharge from secondary care, the child or young person should be reviewed, with their parents or carers and siblings, for any residual problems such as anxiety, aggression or learning difficulties. Treatment plans should be developed for any coexisting conditions.

1.5.2.10 Following treatment with a parent-training/education programme, children and young people with ADHD and persisting significant impairment should be offered drug treatment.

Appendix J NICE (2008) recommendations regarding treatment for school-aged children and young people with severe ADHD

1.5.3.1 In school-age children and young people with severe ADHD, drug treatment should be offered as the first-line treatment. Parents should also be offered a group-based parent-training/education programme.

1.5.3.2 Drug treatment should only be initiated by an appropriately qualified healthcare professional with expertise in ADHD and should be based on a comprehensive assessment and diagnosis. Continued prescribing and monitoring of drug therapy may be performed by general practitioners, under shared care arrangements⁹.

1.5.3.3 If drug treatment is not accepted by the child or young person with severe ADHD, or their parents or carers, healthcare professionals should advise parents or carers and the child or young person about the benefits and superiority of drug treatment in this group. If drug treatment is still not accepted, a group parent-training/education programme should be offered.

1.5.3.4 If a group parent-training/education programme is effective in children and young people with severe ADHD who have refused drug treatment, healthcare professionals should assess the child or young person for possible coexisting conditions and develop a longer-term care plan.

1.5.3.5 If a group parent-training/education programme is not effective for a child or young person with severe ADHD, and if drug treatment has not been accepted, discuss the possibility of drug treatment again or other psychological treatment (group CBT and/or social skills training), highlighting the clear benefits and superiority of drug treatment in children or young people with severe ADHD.

1.5.3.6 Following a diagnosis of severe ADHD in a school-age child or young person healthcare professionals should, with the parents' or carers' consent, contact the child or young person's teacher to explain: the diagnosis and severity of symptoms and impairment the care plan any special educational needs.

1.5.3.7 Teachers who have received training about ADHD and its management should provide behavioural interventions in the classroom to help children and young people with ADHD.

Appendix K NICE (2008) recommendation regarding the duration, discontinuation and continuity of treatment for children and young person with ADHD

1.8.6.1 Following an adequate treatment response, drug treatment for ADHD should be continued for as long as it remains clinically effective. This should be reviewed at least annually. The review should include a comprehensive assessment of clinical need, benefits and side effects, taking into account the views of the child or young person, as well as those of parents, carers and teachers, and how these views may differ. The effect of missed doses, planned dose reductions and brief periods of no treatment should be taken into account and the preferred pattern of use should also be reviewed. Coexisting conditions should be reviewed, and the child or young person treated or referred if necessary. The need for psychological and social support for the child or young person and for the parents or other carers should be assessed.

Appendix L NICE (2008) recommendations regarding transition from child to adult services for young people with ADHD with significant symptoms who are receiving care from CAMHS or paediatric services

1.6.1.1 A young person with ADHD receiving treatment and care from CAMHS or paediatric services should be reassessed at school-leaving age to establish the need for continuing treatment into adulthood. If treatment is necessary, arrangements should be made for a smooth transition to adult services with details of the anticipated treatment and services that the young person will require. Precise timing of arrangements may vary locally but should usually be completed by the time the young person is 18 years.

1.6.1.2 During the transition to adult services, a formal meeting involving CAMHS and/or paediatrics and adult psychiatric services should be considered, and full information provided to the young person about adult services. For young people aged 16 years and older, the care programme approach (CPA) should be used as an aid to transfer between services. The young person, and when appropriate the parent or carer, should be involved in the planning.

1.6.1.3 After transition to adult services, adult healthcare professionals should carry out a comprehensive assessment of the person with ADHD that includes personal, educational, occupational and social functioning, and assessment of any coexisting conditions, especially drug misuse, personality disorders, emotional problems and learning difficulties.

Appendix M NICE (2008) recommendation regarding the treatment of adults with ADHD

1.7.1.1 For adults with ADHD, drug treatment should be the first-line treatment unless the person would prefer a psychological approach.

1.7.1.2 Drug treatment for adults with ADHD should be started only under the guidance of a psychiatrist, nurse prescriber specialising in ADHD or other clinical prescriber with training in the diagnosis and management ADHD.

1.7.1.3 Before starting drug treatment for adults with ADHD a full assessment should be completed, which should include: a full mental health and social assessment; a full history and physical examination, including: assessment of history of exercise syncope, undue breathlessness and other cardiovascular symptoms heart rate and blood pressure (plotted on a centile chart) weight and family history of cardiac disease and examination of the cardiovascular system an ECG if there is past medical or family history of serious cardiac disease, a history of sudden death in young family members or abnormal findings on cardiac examination risk assessment for substance misuse and drug diversion.

1.7.1.4 Drug treatment for adults with ADHD should always form part of a comprehensive treatment programme that addresses psychological, behavioural and educational or occupational needs.

1.7.1.5 Following a decision to start drug treatment in adults with ADHD, methylphenidate should normally be tried first.

1.7.1.6 Atomoxetine or dexamfetamine should be considered in adults unresponsive or intolerant to an adequate trial of methylphenidate (this should usually be about 6 weeks). Caution should be exercised when prescribing dexamfetamine to those likely to be at risk of stimulant misuse or diversion.

1.7.1.7 When starting drug treatment, adults should be monitored for side effects. In particular, people treated with atomoxetine should be observed for agitation, irritability, suicidal thinking and self-harming behaviour, and unusual changes in behaviour, particularly during the initial months of treatment, or after a change in dose. They should also be warned of potential liver damage in rare cases (usually presenting as abdominal pain, unexplained nausea, malaise, darkening of the urine or jaundice). Younger adults aged 30 years or younger should also be warned of the potential of atomoxetine to increase agitation, anxiety, suicidal thinking and self-harming behaviour in some people, especially during the first few weeks of treatment.

1.7.1.8 For adults with ADHD stabilised on medication but with persisting functional impairment associated with the disorder, or where there has been no response to drug treatment, a course of either group or individual CBT to

address the person's functional impairment should be considered. Group therapy is recommended as the first-line psychological treatment because it is the most cost effective.

1.7.1.9 For adults with ADHD, CBT may be considered when: the person has made an informed choice not to have drug treatment drug treatment has proved to be only partially effective or ineffective or the person intolerant to it people have difficulty accepting the diagnosis of ADHD and accepting and adhering to drug treatment symptoms are remitting and psychological treatment is considered sufficient to target residual (mild to moderate) functional impairment.

1.7.1.10 Where there may be concern about the potential for drug misuse and diversion (for example, in prison services), atomoxetine may be considered as the first-line drug treatment for ADHD in adults.

Appendix N NICE (2008) recommendations regarding the duration, discontinuation, and continuity of treatment in adults

1.8.7.1 Following an adequate response, drug treatment for ADHD should be continued for as long as it is clinically effective. This should be reviewed annually. The review should include a comprehensive assessment of clinical need, benefits and side effects, taking into account the views of the person and those of a spouse, partner, parent, close friends or carers wherever possible, and how these accounts may differ. The effect of missed doses, planned dose reductions and brief periods of no treatment should be taken into account and the preferred pattern of use should also be reviewed. Coexisting conditions should be reviewed, and the person treated or referred if necessary. The need for psychological, social and occupational support for the person and their carers should be assessed.

1.8.7.2 An individual treatment approach is important for adults, and healthcare professionals should regularly review (at least annually) the need to adapt patterns of use, including the effect of drug treatment on coexisting conditions and mood changes.

Appendix O Key recommendations from the NICE (2008) guideline on the diagnosis and management of ADHD in children, young people and adults

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- Trusts should ensure that specialist ADHD teams for children, young people and adults jointly develop age-appropriate training programmes for the diagnosis and management of ADHD for professionals who have contact with people with ADHD.
 - Parent-training/education programmes should be offered as first line treatment of ADHD. Healthcare professionals should offer parents or carers of pre-school children with ADHD a referral to a parent-training/education programme as the first-line treatment.
 - Teachers who have received training about ADHD and its management should provide behavioural interventions in the classroom to help children and young people with ADHD.
 - If the child or young person with ADHD has moderate levels of impairment, the parents or carers should be offered referral to a group parent-training/education programme, either on its own or together with a group treatment programme (cognitive behavioural therapy [CBT] and/or social skills training) for the child or young person.
 - In school-age children and young people with severe ADHD, drug treatment should be offered as the first-line treatment. Parents should also be offered a group-based parent-training/education programme.
 - Drug treatment for children and young people with ADHD should always form part of a comprehensive treatment plan that includes psychological, behavioural and educational advice and interventions.
 - Drug treatment for adults with ADHD should always form part of a comprehensive treatment programme that addresses psychological, behavioural and educational or occupational needs
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